VOICE OF THE DIABETIC

A SUPPORT AND INFORMATION NETWORK

The Diabetics Division of The National Federation of the Blind

Volume 7, No. 3 **Summer Edition** **Page 1**

Insulin in uniquely shaped vials would minimize dispensing and dosing errors

by Ed Bryant

Ed Bryant, Editor of the *Voice of the Diabetic*, says that many diabetics would benefit from insulin in differently shaped vials.

Periodically I am asked why different types of insulin aren't packaged in uniquely shaped vials. This would make it far easier for the many diabetics who use a combination of types of insulin to distinguish among them. Given the great number of blind and sighted diabetics in this country alone, I am amazed that insulin manufacturers and/or the Food and Drug Administration (FDA) have not accommodated insulin users with packaging designed for greater safety.

In January 1992 I received correspondence from Ken Carstens of Virginia, MN, who cochairs the Amputation, Prevention and Treatment Committee of our NFB Diabetics Division. Ken included a letter he had sent to Eli Lilly and Company pointing out the danger of confusing vials and suggesting that they be differentiated by shape. Ken's letter dated January 1 is the first of several appended to this article. It is worth noting that as of April 30, 1992 (four months later), he had not received a response from the company.

As ***Voice of the Diabetic*** editor, I later wrote to Eli Lilly and Co. as well as to Novo Nordisk Pharmaceutical Corporation American Division and its company headquarters in Denmark. My letter amplified Ken Carsten's remarks and added that in my view safety ought to outweigh costs; it is also reprinted below together with the three responses from the companies, which I will summarize shortly.

The last letter appended to this article is one I sent to the Commissioner of the FDA urging a change of the relevant regulation. ***Voice*** readers are invited to do likewise.

The president's office at Eli Lilly referred me to Mr. William Gierke, Manager of Pharmaceutical Package Engineering, who called on May 6, 1992. He said that at one time they tried unsuccessfully to put Braille on the vials. Years ago, color was used to distinguish vial labels, but that ended up being a mess due to the confusion of too many colors. Gierke said that the FDA stepped in and made insulin manufacturers use one label color for all vials. He went on to say that Eli Lilly and Company is currently looking at differentiating vials by different color labels because the FDA is once again willing to discuss the matter.

I asked, providing the FDA allowed packaging in differently shaped vials, if he had any idea as to the extra production cost. He said, "I don't know. The round bottles, the ones we use, are tubing vials. An offshaped non-round bottle would be a molded bottle. We would have to gear up to mold bottles. But, as much insulin as we make, the molding would, perhaps be up front quite a bit. But, per product it would probably round off. I really don't think the extra cost would be a factor."

Mr. Gierke said the regulation regarding vial shapes was in the Code of Federal Regulations (CFR). The FDA oversees compliance of regulations relating to development and packaging of medications. The following is from the CFR. Please note the part that addresses insulin vial shapes.

Part 429 – DRUGS COMPOSED WHOLLY OR PARTLY OF INSULIN,

(Continued on page 3)

Voice of the Diabetic *is a national publication of the Diabetics Division of the National Federation of the Blind. It is read by those interested in all aspects of blindness and diabetes. We show diabetics that they have options regardless of the ramifications they may have had. We have a positive philosophy and know that positive attitudes are contagious!*

News items, change of address notices and other magazine correspondence should be sent to (*the editorial suite number has changed from 306 to 309*):

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Blind progress more than blind faith

Kenneth Jernigan serves as the Executive Director for the National Federation of the Blind and the American Action Fund for Blind Children and Adults.

Excerpt of remarks by Kenneth Jernigan, Executive Director, American Action Fund for Blind Children and Adults.

To everything there is a season. There was a time when blind persons were without hope. That time is no mere. During the last generation a dramatic change has occurred for blind persons. A change in the attitudes of those who are blind. And that change continues to gain momentum. The attitudes – not only of blind persons – but of all society are changing. Blindness no longer need be a tragic handicap – if, indeed, it ever needed to be. Today, with proper training and opportunity for blind persons, blindness can be reduced to the level of a mere physical nuisance. The blind are an emerging minority. They are organized, and they are on the move ...

The progress during the last few decades has been rapid and dynamic. The record shows change. There are scars to prove it; enemies to resent it; and friends to confirm it. Blind people no longer sit in their rocking chairs, unless, indeed, they choose to do so. Blind people no longer accept a place on the fringes of society; they are taking their places in the mainstream of the activities of the communities, their businesses, their churches, and country ... The blind face the future with joy in their hearts and heads held high. They insist on being included as partners in society as they enter a new era, the season of tomorrow.

Myth: Individuals who lose their sight late in life are less able to adjust and become self-sufficient than younger persons.

Fact: Blindness is a common problem to be dealt with by senior Americans. It can be reduced to the level of a nuisance, if the individual receives encouragement to be self-sufficient, and some practical advice about skills and methods that can be used for everyday activities and do not require sight.

Implants control diabetes in mice

Washington – A researcher says he has corrected diabetes in mice by implanting pancreas cells under their skin, suggesting a therapy that may one day control the disease in humans without the need for daily insulin shots.

Dr. Paul E. Lacy of Washington University School of Medicine in St. Louis said the laboratory experiment proved that pancreas cells called islets, can thrive and produce insulin while encapsulated in porous tubes implanted in the body.

"This was the first time that anyone had been able to get encapsulated cells to work under the skin," he said. Lacy said if the same result is achieved in experiments on dogs or monkeys, then the technique could be ready for human trials within three years.

Lacy said the key to the islet implant is an inch-long hollow tube that resembles a fiber thread and has the diameter of a toothpick. Holes in the side of the tube are large enough to permit oxygen and nutrients to pass inside to nourish the islet cells and insulin produced by the cells flows out into the blood stream.

The islet cells are protected from rejection by the body because immune system cells, which normally would kill foreign cells, are too large to enter the tube and attack the islets.

Once in place under the skin, the encapsulated islet cells act in the same way as the insulin-secreting cells in a normal pancreas," the researcher said.

"They respond to rising glucose levels," said Lacy. "When the glucose goes up they hold the blood sugar at normal limits."

(Note: This article appeared Friday, December 20, 1991 in the *News-Press*, North Fort Myers, Florida.)

Insulin in uniquely shaped vials

(Continued from page 1)

Subpart B – Packaging and Labeling, 429.10 Packaging

Each batch shall be packaged in immediate containers of colorless transparent glass. Such containers shall be closed with a substance through which successive doses may be withdrawn by hypodermic needle without removing the closure or destroying its effectiveness. The containers and closures shall be sterile at the time the containers are filled and closed. The composition of the containers and closures shall be such that will not cause any change in the strength, quality, or purity of the contests beyond any limit therefore prescribed in applicable standards of strength, quality, and purity. The shape of the containers shall be cylindrical, except that the cross-section of the containers for isophane insulin suspension containing less than 100 U.S.P. Units of insulin per milliliter shall be a rounded square, and the shoulder of the containers for insulin zinc suspension, prompt insulin zinc suspension, or extended insulin zinc suspension containing less than 100 U.S.P. Units of insulin per milliliter shall be hexagonal.

Part of the federal regulation regarding packaging is outdated because insulin has not been packaged in vials containing less than 10cc (1,000 units) for years. Of interest in this discussion is the fact that in the past some insulin was packaged in containers with the cross-section (shoulder) being square, and some with hexagonal shoulders. This federal regulation still exists, which means that the FDA considers it safe for insulin to be packaged in containers with the top cross-section being round, square, or hexagonal.

Mr. Gierke answered many of my questions and provided valuable information relative to my research about insulin vial shapes. He is a professional and well serves his company, Eli Lilly.

Voice readers will, of course, decide for themselves, but in my opinion, the Novo Nordisk responses below were not nearly as complete as those from Eli Lilly and Company. The replies are like those sometimes received from congressional leaders, in that they are quite wordy yet say very little about resolving the issue at hand. They see change as costly and list past failed experiments as reasons to let the issue slide. Often legislators end their replies with something like, "Every consideration will be given to your concern." In my opinion, this is sometimes an indication that change is not a priority.

Mads Oevlisen, President, Novo Nordisk A/S Headquarters in Denmark, and C. Henk Bleeker, President, Novo Nordisk Pharmaceutical Corporation American Division of Princeton, New Jersey, both appointed company representatives to respond to my letters. Their letters stated that in the past the company had considered differentiating the packaging of insulin vials. However, they decided against the idea. Listed below are their reasons and my reactions.

1. Regulatory difficulties: It was suggested that the FDA might not allow the packaging of insulin in uniquely shaped vials because of the concern that confusion may result from too many differently shaped containers for various types of insulin.

The two insulin companies would have to work with the FDA in altering vial shapes. The companies are extremely competitive, but the key word should be SAFETY. Why would there have to be so many differently shaped containers? I suggest using a round vial for short-acting insulin (the same that is currently used); a round vial with the cross-section (shoulder) being a rounded square for intermediate-acting insulin; a round vial with the cross-section (shoulder) being hexagonal for all long-acting insulin. It may not be ideal to have the various long- acting insulins in the same shape vial. However, it would be much better than having all vials the same shape. This is especially true since increasing numbers of physicians recommend the use of more than one type of insulin.

2. Product testing. Novo Nordisk states that extensive product testing would have to be performed to insure that insulin would remain stable in

(Continued on page 4)

Insulin in uniquely shaped vials

(Continued from page 3)

new containers.

I wonder what is meant by extensive, because newly shaped vials would be made of exactly the same material that they are today. As mentioned previously, the current federal regulation regarding insulin packaging already allows containers of less than 10 cc (1,000 units) to have round, rounded squares, or rounded hexagonal shaped shoulders. Of course, there would be testing, but if the vials are constructed from the same materials as they currently are, how extensive would the testing have to be?

3. Higher production cost: Novo Nordisk claims that there would probably be higher production costs because "packaging lines need to be changed between production runs."

Certainly a shape change in packaging is bound to have an initial cost factor. However, I wonder if Novo Nordisk has analyzed the increase in production cost. It appears that the increased cost factor has not been thoroughly investigated. William Gierke of Eli Lilly and Company indicated that cost would probably NOT be a factor due to volume of insulin produced.

Below is the Carstens letter, my correspondence with responses, and a letter to the FDA.

• • •

Virginia, Minnesota
January 1, 1992

Eli Lilly and Company
Indianapolis, Indiana 46285 USA

Dear Sir:

I have been a diabetic for over 45 years and have used your insulin all this time. Many of us diabetics use two types of insulin at the same time to obtain the best glucose control possible. In my case, regular fast-acting insulin for short-term control and NPH for long-term. The bottles are now marked with large R or N on respective bottles.

I have heard of two incidents in the past year where diabetics accidentally got the bottles mixed when filling their syringes. In one case, the diabetic was newly diagnosed with the disease. In this case, there were very serious results, the individual having convulsions with several trips to the emergency ward. The convulsions were so bad that he received broken ribs while being held down and could have lost his life. In the other case, the diabetic was more experienced and was able to correct the situation with no serious results.

I have discussed this situation with many diabetics who have all expressed the opinion that different types of insulin should be in different shape bottles for each insulin.

Many diabetics have lost their sight from the disease, including myself. In this day and age, many diabetics wish to remain independent and draw their own insulin. If the bottles were different shapes as before mentioned, it would be of great help in avoiding overdosing, which could result in serious consequences both to the blind and the sighted.

Respectfully Yours,
Kenneth Carstens

• • •

The following letter was sent to:

Mr. Vaughn D. Bryson, President, Eli Lilly and Company, Lilly Corporate Center, Indianapolis, Indiana 46285.

Mr. C. Henk Bleeker, President, Novo Nordisk Pharmaceutical Corporation, American Division, Suite 200, 100 Overlook Center, Princeton, New Jersey 08540-7810.

Mr. Mads Oevlisen, President, Novo Nordisk A/S, 19 Novo Alle, 2880 Bagsvaerd, Denmark.

Diabetics Division
National Federation of the Blind
Columbia, Missouri
April 6, 1992

Dear Mr. _____:

I am editor of a publication titled ***Voice of the Diabetic.*** With a current circulation of more than 43,000, the ***Voice*** is distributed throughout the United States and in several foreign countries. Among its readers are thousands of blind and sighted diabetics, over 7,000 health professionals, as well as others who have an interest in the disease. I have been asked numerous times why different types of insulins aren't packaged in uniquely shaped vials that could be readily distinguished by sighted as well as blind diabetics.

As you know, there are an estimated 6 million insulin-dependent diabetics worldwide. Of that number, 2 1/2 million reside in the United States. These consumers could easily distinguish between vials of various kinds of insulin if the containers were each shaped differently. For example, short-acting insulin could be packaged in a round vial, intermediate-acting insulin could be in a square container, and long-acting insulin could be housed in a polygon shaped container. I'm sure you know that most diabetes doctors now recommend multiple injections with mixed insulins.

It is estimated that more than 12,000 diabetics in the United States alone become blind each year from diabetic retinopathy. If the vials were shaped according to the type of insulin, blind consumers could independently draw the correct type of insulin with confidence. As you know, inadvertent use of the incorrect type of insulin can have serious or even fatal consequences. Rubber bands or tape can be used to mark vials, but the rubber bands can break and tape may become detached.

In my work as editor of the ***Voice*** and in attending diabetes seminars, I have heard diabetics, both sighted and blind, say that it is easy to get different types of insulin bottles mixed up. When the diabetic is running late, the baby is crying, or whatever, the chance of drawing up an incorrect type of insulin increases. With insulins packaged in uniquely shaped containers, the individual would be far more likely to use the correct type of insulin.

Like most type I diabetics, I occasionally experience insulin reactions. I recall one incident during which I consumed simple sugar to combat the low. While still a little disoriented, I foolishly attempted to draw insulin. I wasn't cognizant of what I was doing. Fortunately, when I came out of the low, I hadn't made the injection because I could not determine with certainty the amounts or types of insulin I had drawn. If the insulin vials had been of different shapes, I would have been far more likely to have drawn the correct types of insulin.

HAVE YOU CONSIDERED PACKAGING INSULIN IN DIFFERENTLY SHAPED VIALS? From a marketing standpoint, providing different shapes of containers would be of minimal cost, if any, to the manufacturer and would be extremely beneficial to consumers. The bottom line should not be concerned so much with cost as with SAFETY unless there is some factor of which I am unaware. I don't understand why different types of insulin were not packaged in differently shaped containers long ago.

I would appreciate a response regarding this matter. I look forward to hearing from you.

Most sincerely,
Ed Bryant
First Vice President, Diabetics Division
Editor, ***Voice of the Diabetic***

• • •

Eli Lilly and Company
Indianapolis, Indiana
April 9, 1992

Mr. Ed Bryant, First Vice President
Diabetics Division

Dear Mr. Bryant:

Thank you for your letter regarding insulin packaging. I appreciate the information you provided as background for your inquiry. Mr. William Gierke, Pharmaceutical Packaging Engineering, has been asked to respond to your questions.

We appreciate your taking the time to write and wish you continued success with your publication, ***Voice of the Diabetic.***

Sincerely yours, Vaughn D. Bryson, President
cc: Mr. William Gierke

• • •

Novo Nordisk
Princeton, New Jersey;
April 14, 1992

Ed Bryant, First Vice President
Diabetics Division

Dear Mr. Bryant:

Mr. Bleeker has referred your letter suggesting changing insulin vial shapes to reduce the chance of dosing error. Your letter brings up an interesting issue, and it is not the first time a suggestion of this nature has been made.

Several years ago, color coding of insulin labels was proposed as a way of reducing dispensing and dosing errors. At that time, however, the FDA would not permit this because of the concern that coding might get out of hand with too many colors. Specifically, the FDA believes that there will be confusion if all manufacturers do not use the same color codes for each type insulin. It is possible that the FDA might also share this view regarding unique vial shapes for different insulin types.

Unlike changing label colors, changing vial shapes requires a substantial production change. Extensive product stability testing needs to be performed to assure that insulin will remain stable in the new container. The FDA must also approve the change before production can start. In addition, production equipment will need to be retooled and production costs might be higher as packaging lines need to be changed between production runs.

As a responsible health care company, Novo Nordisk Pharmaceuticals Inc. is committed to manufacturing and marketing products which best meet the needs of its customers. Your suggestion is very much appreciated, and it will receive consideration by our Marketing Department.

Sincerely,
Robert J. Moss, Pharm.D.
Director, Professional Services
cc: Paul Allen

• • •

Novo Nordisk
Bagsvaerd, Denmark
April 21, 1992

Ed Bryant, First Vice President
Diabetics Division

Dear Mr. Bryant:

Mr. Mads Oevlisen has given me your letter to him of April 6, 1992 for consideration and reply.

Let me first thank you very much for having sent us such an interesting letter in which you suggest that Novo Nordisk might wish to consider to pack our different types of insulin in differently shaped vials. This might minimize, or even eradicate, the possibility of patient errors in drawing another type of insulin than intended from a vial. The problem is for obvious reasons of particular relevance for diabetic patients who have impaired vision or are blind.

Novo Nordisk has always been committed to offering the best products and service to the diabetic community, and we have on many occasions considered to differentiate the packaging of our vials e.g. along the lines which you have suggested. We have, however, always ended up deciding to stay with a similar packaging of our different insulin types,

If you or a friend would like to remember the Diabetics Division of the National Federation of the Blind in your will, you can do so by employing the following language:

"I give, devise, and bequeath unto Diabetics Division of the National Federation of the Blind, 1800 Johnson Street, Baltimore, Maryland 21230, a District of Columbia nonprofit corporation, the sum of $_____" or "_____ percent of my net estate" or "the following stocks and bonds: _____") to be used for its worthy purposes on behalf of blind persons."

the reasons being regulatory difficulties in many countries, higher production costs and, in particular, the fact that there today are so many different insulin types on the market that it will be close to impossible to design clearly distinguishable differently shaped vials. In fact, we believe that an even higher degree of confusion might occur, and this should of course not be the end result.

You may have noticed that Novo Nordisk was the first company to bring insulin pens to the market. These pens have clearly facilitated insulin injections and to some extent made it easier to distinguish between the different insulin types. Recently, we have introduced into some markets a unique disposable insulin injection device which in Denmark is called NovoLet. NovoLet is a prefilled insulin pen which can be discarded when it is empty. NovoLet comes with a very attractive colour and tactile coding that makes it possible for the patients to distinguish between the different insulin types with which it is prefilled. So, while we have not yet been able to make our insulin vials easily distinguishable, this problem has been elegantly solved with NovoLet.

Once again, many thanks for writing to Novo Nordisk. I hope my answer has been of some help to you. If you need further information, please don't hesitate to write to Novo Nordisk again.

Kind regards
yours sincerely
Claus Kuhl, M.D., Ph.D.
International Medical Affairs
Group Vice President
Health Care Group
cc: Mr. Mads Oevlisen
Mr. Jorgen Elnegaard

• • •

I would appreciate Voice of the Diabetic readers writing to the commissioner of the Food and Drug Administration. If you agree that the packaging of insulin in differently shaped containers would be safer and minimize errors, the following letter may serve as a guide. It is best to be specific. No matter the style of your letter, it is important that you express your opinion to Commissioner Kessler of the FDA. Also, please send a copy of your correspondence to me for documentation purposes. Any response received from the FDA by our Diabetics Division will appear in the next issue of the Voice.

Any correspondence sent to the Food and Drug Administration should be directed to: Mr. David A. Kessler, Commissioner of Food and Drugs, Food and Drug Administration, 5600 Fishers Lane, Rockville, MD 20857.

Diabetics Division
National Federation of the Blind
Columbia, Missouri
May 15, 1992

Mr. David A. Kessler, Commissioner
Food and Drug Administration
Rockville, Maryland

Dear Commissioner Kessler:

I am editor of the ***Voice of the Diabetic,*** a nationally distributed publication of the Diabetics Division of the National Federation of the Blind. With a circulation of more than 43,000 that includes over 7,000 hospitals and health professionals, the ***Voice*** informs those interested in diabetes about ramifications of the disease and serves as a forum for concerns of diabetics. According to a 1992 report *(Diabetes in the United States, a Strategy for Prevention),* the Centers for Disease Control estimates that 15,000 persons become blind each year from diabetic retinopathy. In my duties as editor of the ***Voice,*** I am often asked why different kinds of insulin aren't packaged in differently shaped vials that would allow both sighted and blind diabetics to readily distinguish between the different types of insulin. I am writing to request that the shape of insulin containers be altered for consumer safety.

Most physicians who specialize in diabetes now recommend multiple injections with different types of insulins. Because all insulin vials currently have the same shape, it is difficult for blind and visually impaired diabetics to distinguish between the various insulin types. Blind as well as sighted diabetics can inadvertently make dispensing and dosing errors which can result in serious and possibly fatal consequences. The key word should be SAFETY.

I understand the regulation cited below is discretionary and that you have the right to change it should you find a proposal judicious. Insulin packaging is covered by the Code of Federal Regulations (CFR). Part 429 – DRUGS COMPOSED WHOLLY OR PARTLY OF INSULIN Subpart B – Packaging and Labeling 429.10 Packaging.

To alleviate or minimize inadvertent errors, I propose that you authorize: all short-acting insulin continue to be packaged in cylindrical shaped containers; all intermediate acting insulin be packaged in cylindrical shaped containers except that cross-sections (shoulders) be rounded squares; all long-acting insulin be packaged in cylindrical shaped containers with hexagonal shoulders.

Although insulin is no longer packaged in vials of less than 10 cc, the CFR regulation allows some containers to have non-rounded tops. This indicates that since differently shaped containers have been used in the past and were thoroughly analyzed, the contents were safe for use by diabetic consumers. Modified vials would allow users to determine the contents tactually, thereby increasing safety.

Changing the shape of insulin containers should not greatly affect the cost to consumers. Mr. William Gierke, Manager of Pharmaceutical Package Engineering for Eli Lilly and Company, has stated that although the initial cost for new packaging design would be expensive, it should round off per product. He said, "I really don't think the extra cost would be a factor."

I ask that you give strong consideration to changing the CFR regarding insulin packaging so that the product could be housed in uniquely shaped containers.

I anxiously await your reply to the aforementioned matter, so it can be shared with readers of our publication.
Respectfully,
Ed Bryant
First Vice President, Diabetics Division
Editor, ***Voice of the Diabetic***

One of the responsibilities of the National Federation of the Blind Diabetics Division is to initiate change that will help diabetics. If you feel that redesigning insulin vials will be beneficial to diabetic consumers, I again strongly urge that you contact Commissioner Kessler. I personally feel that this issue is important and welcome all questions and comments.

Board Members

The Diabetics Division of the National Federation of the Blind.

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Tom Ley, Secretary, 2514 Deas St., Bossier City, LA 71111; Phone: (318) 746-0356

The cost benefits of eye research: diabetic retinopathy as a model

by Jonathan C. Javitt, M.D.

(Editor's Note: The following are portions of an address made on Sept. 16, 1990 at the Science Writers Seminar in ophthalmology, Universal City, Calif. This conference was sponsored by Research to Prevent Blindness.)

• • • While it might seem obvious that diabetic patients should receive appropriate screening and treatment, researchers have found that only 58 percent of those in need of sight saving care actually receive it. Reasons for failing to receive vitally needed care are: lack of awareness regarding the seriousness of diabetic eye disease, lack of information regarding the availability of treatment, and lack of financial resources.

While many Americans have insurance that pays for part or all of their health expenses, 37 million Americans are uninsured. Approximately eight percent of patients with diabetes mellitus have no medical insurance. Those who do have coverage are often faced with exceptions and exclusions in their policies for their diabetic disorders. Even if the government entirely funded this type of preventive program, our results show that the savings would still be over $100 million. As physicians, our first concern must be the welfare of our patients, not whether we are getting a monetary return on our health care investment. Yet, cost is increasingly intruding on policy decisions that affect care. To the extent that the best level of care for the patient also represents an actual cost savings, this philosophic and moral dilemma is avoided. All too often, health care is seen as a simple expense, rather than an investment. Those interventions that are strongly cost saving should be identified in order to place overall health expenditures in better perspective. As payment for medical care has shifted from the individual to the corporation and the government agency, our argument must often be made in the terms that fiscal managers best understand; namely the bottom line.

• • • The major causes of permanent vision loss, glaucoma, diabetic retinopathy, and age related macular degeneration are chronic, irreversible diseases. Prevention of visual deterioration and blindness in those conditions entails an investment of health resources over a span of years and a return in years of sight preserved.

• • • Our primary methodologic approach is the Prospective Population Health Event Tabulation (PROPHET) modeling system that we are developing in order to access outcomes in populations with chronic, progressive eye diseases. PROPHET is a Monte-Carlo simulation tool that models the costs and outcomes associated with treatments to preserve sight in patients who are at continued risk of co-morbidity and mortality. The model is specifically designed to allow for multiple intermediate disease states, treatments, and clinical endpoints within the course of a disease.

The model begins with a hypothetical cohort (group) of patients with diabetes and follows the likely progression of disease over the course of their lifetimes. With each passing year, the probability of developing eye disease or losing sight is drawn from existing epidemiologic studies. Similarly, data on the effectiveness of screening and treatment interventions are drawn from national multicenter trials and clinical studies.

Once all relevant data are assembled into the simulation model, we can predict the effectiveness and cost effectiveness of alternative screening and treatment approaches. We can similarly predict the effect of changes in costs of care, effectiveness of treatment, and changes in the natural history of the underlying disease. For instance, if better control of blood sugar is shown to decrease the likelihood of diabetic eye disease or to delay its onset, the model can incorporate that new information.

• • • Our initial interest in this area of research came about when a 36-year-old substitute teacher from Camden, New Jersey came to us complaining of blurry vision and asking for new glasses. In fact, his glasses were fine. He had proliferative diabetic retinopathy with blood vessels leaking into the retina, or back part of the eye. As stated before, effective treatment is known to prevent vision loss for patients with this condition. However, because he was a part-time substitute teacher, he had no health insurance. He was too young for Medicare and earned too much money to be eligible for Medicaid. Therefore, like 37 million other Americans, he had no ability to pay for care that was likely to preserve his sight. Of course, in his case, we were able to treat him at no charge. However, this is an impractical approach for 37 million of our citizens. His situation prompted us to ask whether it was more cost-effective for the government to provide sight-saving care, or to pay for costs of blindness. While this may seem like hard-hearted economic analysis, analyses of this type are essential in allocating scarce health resources. By way of follow-up, that teacher has full vision today.

I'm not finished yet

by Bonnie Ruppert

In 1956 at age 14, I was diagnosed as having diabetes. I was already familiar with the malady because my dad had been diagnosed with diabetes four years earlier, when he was 39. Even so, I had a rough time getting my disease under control.

When my doctor started me on oral medication, a new treatment at that time, he was unaware that young diabetics are unable to use that type of medication. Lack of control because of inappropriate medication caused me problems. I remember my dad telling me that my band teacher in high school thought that I had talent, but that I was lazy. I was feeling terrible at the time. It wasn't long before I was hospitalized because of high glucose. I went into a coma. Because I had been on strict diet, it was hard for my family to understand how my diabetes could be out of control. When I started taking insulin in the hospital, I was able to control my diabetes. We are much more fortunate these days when so much about diabetes is understood and we have ways of keeping track of the glucose. (Checking glucose levels with a doctor once a month is hardly enough. I am shocked to find that many elderly people still carry on this practice.)

I married after graduating from high school. A year later, I gave birth to our first daughter, who weighed ten pounds, ten ounces, and was delivered naturally. Two years later, during labor with our second baby, the placenta separated about an hour before delivery, causing her to be stillborn. (I had false labor the week before but was sent home to wait. These days, I'm sure the baby would have been saved; but, at that time, I was going to a G.P. and none of the modern kinds of testing were available.) Three years later, our third daughter was born by C-section. She weighed ten pounds, one and one-half ounces and was red-headed from the start. I got along fine with all my pregnancies, and I am thankful for that. When young, one doesn't know all that can go awry.

All went well until 1970, when I was 28 years old. I hadn't noticed that my vision was slowly becoming more blurred and that distant objects were become more indistinct. When I raised my head after washing my hair, I noticed a spot in my right eye, which slowly blinded that eye. I was sent to Denver, where I was diagnosed as having an advanced stage of retinopathy. To save my left eye, within a short time I underwent two treatments. By the time the doctor decided that I should undergo a third treatment, the laser had come into use, and I was sent to another hospital for laser treatment. In those days, it was ordered that I return home by airplane instead of traveling by car for five hours. Flying was most enjoyable and comfortable even though it was in smaller planes. For many years, we returned every three months for checkups. The doctor was usually pleased with my progress. Following the treatments, I was ordered to do nothing at home. I spent many long hours being able to do very little but think and pray. I always prayed that I would be able to see my girls grow up, graduate from high school, and make lives for themselves. God has been good to me because I have been able to see, although very poorly, not only my daughters but even my four grandchildren.

It took six whole years before my right eye had cleared enough to where I could see. The hemorrhaging occurred close to the optic nerve. Now, there is so much scar tissue that my ophthalmologist cannot see beyond the damage that is being done by high pressure that has developed these past few years. I have tried several kinds of eye drops for glaucoma, but none seem to work. Despite this, the last check indicated that the pressure had, fortunately, been reduced from 29 to 24. I am anxious to see if the same is true at my next check. In December, 1990, I began taking the nutrients Ginkgo Biloba and Germanium, two health food supplements, which have been known to help such problems. I feel this may be of help to someone with the same problem.

The sixth year passed with my right eye clearer but, by then, my left eye had filled with scar tissue, and a hole in the macula had developed. Its prognosis is to only worsen. It may be my imagination, but it seems that my left eye is clearer than it was. I feel the credit for that goes to the Ginkgo.

I have been almost completely blind, but if there is even a bit of light or ability to see images, it seems wonderful to me. My right eye is still functioning, but the retina is attached in only one place and is hanging on like a tent. Also, a cataract which had been dormant for twenty years is now rapidly developing. I am walking on eggshells, but I am not finished yet!

In the '80s, I acquired my first glucose monitor, and it became evident I needed a big change in my insulin. In my area of the country, we are not blessed with specialists who deal with diabetics and our problems. Doctors make suggestions, and then the "trying and erroring" is up to us to deal with. Perhaps this is the same all over the country. About ten years ago, I began taking two shots a day. I don't wake up at night, and if I have a reaction while sleeping, it's almost devastating. So far, my husband has always come to my rescue, many times with glucagon. I need to have a glucose reading of at least 200 before going to bed, or it means trouble of the most serious kind. If I don't take a

shot at supper, the glucose seems to rise after going to bed. Am I the only one with such a problem?

Health insurance poses difficulties for me. I am unable to work, and I had to give up driving years ago. Fortunately, I live on a farm where there is enough to do. Insurance that I had went up to over $6000 a year, which we could not afford. After fulfilling the required six-month waiting period, I did manage to get on with Comprehensive Health Insurance of Nebraska. It costs $192.00 a month. I wonder if this is standard for diabetics. I had never collected anything before for medications, but now I have to or I wouldn't be able to survive.

We live one day at a time and cannot waste time worrying about tomorrow. My dad was the diabetic, but my mom passed away in 1988 after being on dialysis for four years. Dad had a lot of back pain in his latter years before he died in 1989. I wonder now if his back pain was due to neuropathy that the doctors failed to diagnose. My folks were both in their 70's. My age is up to those who want to do some figuring. Ha!

I enjoy the ***Voice***! I have looked for many years, and it is the best publication I have ever found. Thank you to all who are responsible.

From the Editor: I phoned Bonnie Ruppert after receiving her article to answer some of her questions. Regarding insulin reactions while sleeping: A device called Sleep Sentry is worn like a wrist watch and may be helpful. It detects perspiration during a reaction and sounds an alarm to alert the wearer that a reaction is in progress. Sleep Sentry costs $275.00 and can be ordered from Diabetes Supplies, Inc., 8181 North Stadium Dr., Houston, TX 77054; phone: 1-800-622-5587. Bonnie, you are not alone. Many diabetics have reactions during sleep. Most diabetics can avoid this problem by taking the correct amount and type of insulin. Monitoring blood sugar can often predict trouble that may occur during sleep. Check with a diabetes specialist about medication regimen. It is essential for all diabetics to educate themselves about diabetes, especially those in rural areas who may not be able to contact a specialist on a regular basis. Regarding insurance for diabetics: Acquiring health insurance is a major problem for diabetics because the carriers know that anyone with diabetes is at risk for complications. Diabetics almost always pay an exorbitant amount for individual health insurance. Bonnie, I can't answer what is standard for diabetics because costs vary between companies and from state to state. For an answer to your question, contact the State Insurance Commissioner located in your state capital. The Diabetics Division Legislative Issues Committee is working on an article regarding health insurance for diabetics which will appear in a future issue of the **Voice**.

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James Gashel, Director of Governmental Affairs, National Federation of the Blind, works diligently to improve the lives of the blind.

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From: Members of the National Federation of the Blind

To: Members of the 102nd Congress

Re: The Blind: Legislative Priorities for the 102nd Congress, Second Session

Public policies and laws affecting blind people have a profound impact throughout our society. Most people know someone who is blind. It may be a friend, a family member, or a co-worker on the job. The blind population in the U.S. is estimated to exceed 750,000. Fifty thousand Americans become blind each year. By themselves these numbers may not seem large, but the social and economic consequences of blindness directly touch the lives of millions. Less directly, blindness affects us all.

Blind people as a group share a unique struggle. More than being a matter of physical disability, the real problems of blindness are lack of good training, lack of opportunities, and lack of correct information about blindness among employers and members of the public at large. If a blind person has proper training and opportunity, the physical loss of eyesight itself can be reduced to the level of a mere nuisance.

Public policies and laws that result from misconceptions about blindness or lack of information are often more limiting to the blind than loss of eyesight itself. This is why we have formed the National Federation of the Blind. The Federation is a private-sector resource of knowledge, encouragement, and support for the blind and for anyone (blind or not) who wants to join in the effort we are

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making to win understanding and opportunity.

Blind people are well organized at the community and grassroots levels throughout the United States. Our policy positions are developed and determined by vote of the blind themselves. This is why the Federation is known by lawmakers and the public as the "voice of the nation's blind." Our priorities for the second session of the 102nd Congress express our assessment of current issues requiring action by Congress on behalf of blind persons of all ages.

(1) Congress should amend the Rehabilitation Act of 1973 to establish the client's right of choice as a policy to be followed in selecting agencies to provide rehabilitation services. Blind persons eligible for rehabilitation have the right to receive services, but counselors assigned by designated state agencies are empowered to make most of the planning decisions and arrangements for service. The client's views must be considered, but counselors make all of the final decisions. Funds to support rehabilitation can be and are withheld if the client does not cooperate. Cooperation means accepting the rehabilitation counselor's prescribed plan for service, whether or not the client concurs with the counselor's prescribed plan. This system often fails, of course, because of client resistance to mandated services.

The proposed legislation will achieve better matching of clients with compatible programs by empowering them to take charge of selecting sources for all services. As persons with disabilities begin to experience and exercise newly won legal rights, there will be a growing demand and need for services chosen by clients, not by agencies. Students who receive Federal aid to attend post-secondary institutions choose their own schools and select their courses of study. Elderly and disabled recipients of health services paid for by Medicare choose the doctors they will see, and the bills are paid by Medicare. Not so in rehabilitation. Congress should change this policy. For more details and a description of the need for this legislation, see the fact sheet entitled "EMPOWERMENT IN REHABILITATION: EXPANDING CHOICES FOR BLIND ADULTS."

(2) All members of Congress should advise the Secretary of Education to remove NAC from his list of recognized accrediting agencies. NAC is the National Accreditation Council for Agencies Serving the Blind and Visually Handicapped. "Accreditation" is supposed to mean that approved programs are of a high quality, but the record of NAC's performance in the blindness field shows that in the case of NAC, precisely the opposite is true. This is why so many blind people and agencies serving the blind oppose a petition filed by NAC to continue its recognition by the U.S. Secretary of Education.

NAC's goal is to gain control over the distribution of Federal funds through (1) being recognized by the Secretary of Education as the national accrediting agency in the blindness field, and (2) convincing Congress to enact legislation to require accreditation for all programs that receive Federal financial assistance under the Rehabilitation Act of 1973. Both of these actions are strongly opposed by blind people and by agencies serving them. For more details and a list of reasons why NAC should not be recognized by the Secretary of Education, see the fact sheet entitled "POINTS IN OPPOSITION TO RECOGNITION OF NAC BY THE U.S. SECRETARY OF EDUCATION.'

(3) Congress should amend Section 8(a) of the Small Business Act to include individuals with severe disabilities as a defined minority group for purposes of eligibility in the Minority Small Business and Capital Ownership Development Program. The Section 8(a) program is designed to foster business ownership by individuals who are both socially and economically disadvantaged, and to promote the competitive viability of businesses owned and operated by them. To achieve these goals, Section 8(a) authorizes the Small Business Administration (SBA) to enter into all types of contracts with government departments and agencies for supply, service, construction, and research and development. Small Business concerns, owned and controlled by socially and economically disadvantaged persons can be eligible to receive subcontracts to fulfill SBA's procurement obligations. Technical assistance is also made available to minority small business concerns.

This proposal is simply the recognition of disability as a condition of defined minority status for participation in SBA's targeted efforts to provide economic and technical assistance to members of minority groups. The social and economic disadvantages which accompany disabilities are well-known and should be beyond dispute. Blind persons have traditionally had few opportunities to become employed and even fewer opportunities to establish and maintain their own businesses. Yet, SBA has not recognized the blind (or individuals with disabilities in general) as being socially and economically disadvantaged. The problem for SBA has been to define disability and the extent of the class of individuals included. Another problem has been SBA's lack of legal authority to incorporate such a definition in the absence of a clear legislative mandate. The Americans with Disabilities Act (Pub. L. 101-336) now provides the basis for a legislative mandate, although a definition for "severe disability" must be used to meet the more limited purposes of the SBA program. For more details and an explanation of the need for this legislation, see the fact sheet entitled "MINORITY STATUS AND RIGHTS: A PROPOSAL FOR BUSINESS OPPORTUNITIES AND JOBS."

Blind people are asking for your help in securing positive action by Congress in the areas outlined here. Legislative proposals will be offered to achieve each of our specific objectives. Many priorities confront this session of Congress, but the needs of the nation's blind must not be overlooked.

We of the National Federation of the Blind stand ready to assist our Representatives and Senators to understand our needs and to take meaningful action to address them. In partnership with the National Federation of the Blind, each member of Congress can help build better lives for the blind both today and in the years ahead.

FACT SHEET
Empowerment in Rehabilitation:
Expanding Choices
for Blind Adults

BACKGROUND: Federal support for rehabilitation of the disabled began in 1920, but programs for the blind did not receive Federal assistance until 1943. At that time, job training and employment assistance were the goals sought through rehabilitation, and even today these goals remain as the central focus of the program. Federal spending for rehabilitation has increased substantially in recent years, but the unemployment rate among working-age blind people remains unacceptably high. Laws against discrimination may help, but relevant, individualized services, designed to prepare blind persons for work, must also be provided.

EXISTING LAW: The Rehabilitation Act of 1973 (Pub. L. 93-112), as amended, authorizes most of the current Federally supported rehabilitation programs. In excess of $1.7 billion in Federal financial assistance is distributed to the states under Title I of the Rehabilitation Act. Titles II and XVI of the Social Security Act also authorize the use of additional funds to pay for the costs of rehabilitation services for disabled and blind people who receive Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) benefits.

A state cannot receive Federal funds or Social Security payments for rehabilitation unless there is a specific state agency designated to conduct the rehabilitation program. States have the option of designating one agency specifically to serve the blind and another to serve persons with other disabilities. All rehabilitation services must be obtained through the designated state agency. The policies and procedures of the agency govern the provision of services.

Regardless of individual preferences, blind persons seeking rehabilitation (referred to as "clients") must use the agency designated for them. A counselor is assigned to represent the agency and to oversee the provision of services. The basis for each client's rehabilitation program is supposed to be an individualized plan jointly developed by the counselor and the client, but options for the clients to select among sources for training are not offered by most state agencies. Many state agencies have distinct policies against accepting client choices in the selection of any program to provide any service. This lack of a free choice is a major deterrent to effective and responsive training and employment services, leaving almost eighty percent of employable blind people largely outside of our nation's work force.

PROPOSED LEGISLATION: Congress should amend the Rehabilitation Act of 1973 to establish the client's right of choice in selecting agencies to provide rehabilitation services. Blind persons eligible for rehabilitation have the right to receive services, but personnel of the designated state agencies are empowered to make most of the planning decisions and arrangements for service. Joint planning by rehabilitation clients and counselors is required in section 102 of the Rehabilitation Act, but all final decisions about anyone's rehabilitation plan rest with personnel of the designated state agencies.

The "client's right of choice" provision would maintain the principle of individualized planning with joint participation by clients and counselors. The difference would be that services provided under an individualized plan could only be obtained from sources of the client's choice. Few decisions more fundamentally affect the outcome of rehabilitation. The client's compatibility with the philosophy, policies, and personnel of any training program is highly individualized. Current practices in rehabilitation largely ignore this fact. The proposed legislation will achieve better matching of clients with compatible programs by empowering rehabilitation clients to take charge of selecting sources for all services they receive.

NEED FOR LEGISLATION: Opportunities for persons with disabilities (including the blind) are expected to expand dramatically during the decade of the 1990s and beyond. The recently enacted Americans with Disabilities Act will provide a major impetus for growth and change, but existing programs (such as rehabilitation) will face new challenges brought on by newly emerging demands. Experience

shows that the growing opportunities which become available for the blind will lead to rising expectations by the blind to enter fields of endeavor previously closed to them. Effective rehabilitation programs will provide the kind of support and training necessary for the blind to take full advantage of expanding opportunities only if they are flexible enough to respond to individual needs.

Policies of most state agencies now mandate that services can only be obtained from agency-specified programs. Client preference is of little consequence. Decisions are most often made to suit bureaucratic convenience or arbitrary state rules. But as persons with disabilities begin to experience and exercise their new rights, there will be a growing demand and need for services chosen by clients, not by agencies. Students who receive Federal aid to attend post-secondary institutions choose their own schools and select their courses of study. Elderly and disabled recipients of health services paid for by Medicare choose the doctors they will see, and the bills are paid by Medicare. Yet in rehabilitation, client choices are subordinated to counselor decisions and agency policies.

Restrictive approaches in rehabilitation are inconsistent with the modern policies of rights and empowerment for persons with disabilities. Empowerment implies choice. This is the next logical step in the evolution of rehabilitation to support empowerment and independence. The right of choice is a cost-effective approach which Congress should now enact.

FACT SHEET
Points in Opposition to Recognition of NAC by the U.S. Secretary of Education

BACKGROUND: NAC is the National Accreditation Council for Agencies Serving the Blind and Visually Handicapped. "Accreditation" is supposed to mean that approved programs are of a high quality, but the record of NAC's performance in the blindness field shows that in the case of NAC, precisely the opposite is true. This is why so many blind people and agencies serving them oppose a petition filed by NAC to continue its recognition by the U.S. Secretary of Education.

Accrediting agencies may be recognized only for the accreditation of postsecondary institutions or programs when eligibility for Federal assistance requires accreditation. NAC's goal is to gain control over the distribution of Federal funds for all programs serving the blind. However, first the Secretary of Education would have to continue to list NAC as a recognized accrediting agency, and second Congress would have to enact legislation to require accreditation for all programs that receive Federal financial assistance under the Rehabilitation Act of 1973. Both of

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these actions are strongly opposed by blind people and by agencies serving them.

NAC IS NOT ACCEPTED IN THE BLINDNESS FIELD AND SHOULD NOT HAVE CONTROL OVER FEDERAL FUNDS: Although NAC offers to accredit all agencies and schools serving the blind, most programs have chosen not to become involved. In twenty-five years of trying to become accepted, NAC has accumulated only ninety-six accredited member agencies, with a nearly twenty-five percent dropout rate. NAC's membership includes less than twenty percent of the programs eligible to apply for accreditation. Federal funds, used to establish and support NAC in its early years, were withdrawn in 1975 in the face of low agency acceptance of the NAC standards and consumer concerns raised about the NAC accreditation process.

These conditions still exist. As a result, NAC's membership is now declining, and financial support has fallen sharply. Seven agencies ended their affiliation with NAC during 1991. At the same time, both of NAC's major funding sources — the American Foundation for the Blind (AFB) and National Industries for the Blind (NIB) — withdrew their financial support, effective in July, 1991. As a result NAC's income has plummeted by almost sixty percent, and the organization is in virtual bankruptcy.

REASONS WHY NAC SHOULD NOT BE LISTED AS A RECOGNIZED ACCREDITING AGENCY: The Secretary of Education has published criteria for the recognition of accrediting agencies. Any agency submitting a petition for recognition must meet all of the criteria. As specified below, NAC fails the test in several important respects.

(1) Membership in NAC is unrelated to eligibility for Federal funds — Some Federal programs require accreditation by a recognized agency as a condition of eligibility for financial aid. However, in the case of programs serving the blind, program performance and accountability for the use of funds are audited directly by both state and Federal agencies. Since direct monitoring is used in lieu of accreditation, there is no need for NAC to be recognized by the Secretary. Accreditation programs that are unrelated to the distribution of Federal funds do not meet the Secretary's criteria for recognition.

(2) NAC has not earned national respect and recognition among agencies and professionals in the blindness field — In its twenty-five years of existence, NAC's performance record has been marked by discord and disunity. It is generally agreed that programs for the blind have not been improved by affiliation with NAC, and many have been found in violation of state or Federal laws while being fully accredited. NAC's current members represent fewer than one-sixth of the agencies that could potentially seek affiliation. The vast majority of these agencies have consciously decided that membership in NAC is not in their best interest. Accrediting agencies that are not accepted by programs in their field do not meet the Secretary's criteria for recognition.

(3) NAC lacks the resources necessary to maintain a credible accreditation program — NAC's annual spending rate for each of the last two fiscal years has exceeded $460,000. Income for the same period has trailed spending by almost $60,000. NAC's budget adopted for fiscal year 1992 has been reduced to $216,065, due to the withdrawal of support from AFB and NIB. At the same time, even when funded at above $400,000, NAC has been unable to evaluate its member agencies at the required periodic intervals.

Accreditation of most agencies is extended without complete evaluation and in many instances with no evaluation at all. During 1990 NAC reviewed eight agencies and extended eighteen. During 1991 twenty agencies were extended. Most of them are supposed to be reviewed during 1992. Twelve of them were carried over in a backlog built up from previous years. In addition to these extended agencies, there are another twenty coming due for review this year. Some of them were also extended from previous years. It is clear that the backlog is now out of hand and NAC does not have the resources to fulfill its commitments. Scheduled updating of accreditation standards has also been put off due to the lack of resources. Agencies such as NAC that do not have the resources to maintain a credible accreditation program do not meet the Secretary's criteria for recognition.

HOW MEMBERS OF CONGRESS CAN HELP: Write to Lamar Alexander, Secretary of Education, to request that NAC not be listed as a recognized accrediting agency. Advise the Secretary that NAC does not meet the criteria for recognition and therefore should not be retained on the list.

FACT SHEET
Minority Status and Rights: A Proposal for Business Opportunities and Jobs

BACKGROUND: Blind persons and persons with disabilities in general have traditionally had few opportunities to become employed and even fewer opportunities to establish and maintain their own businesses. This does not reflect a general lack of ability among this population. It does reflect a lack of opportunity and financial support necessary to achieve success in the competitive business world. Prejudices and fears of employers have left nearly eighty percent of the employable blind population either unemployed or substantially underemployed.

Congress has recently sought to address this situation by enacting the Americans with Disabilities Act. When the employment provisions of this Act become effective in 1992, employers having twenty-five or more employees will be prohibited from discrimination on the basis of disability. Employers having fifteen or more employees will eventually be covered. Regardless of enforcement activities, this Act is expected to improve work force opportunities for persons with disabilities. But complete equality will require more than employment rights. This fact has been recognized in our government's efforts to underwrite and support economic development programs among members of other traditionally disadvantaged minorities.

EXISTING LAW: Sections 8(a) and 7(j) of the Small Business Act establish a Minority Small Business and Capital Ownership Development Program to be conducted by the Small Business Administration (SBA). This program is intended in part to foster business ownership by individuals who are both socially and economically disadvantaged; and to promote the competitive viability of businesses owned and operated by them. To achieve these goals, Section 8(a) authorizes SBA to enter into all types of contracts with government departments and agencies for supply, service, construction, and research and development. Small business concerns owned and controlled by socially and economically disadvantaged persons can be eligible to receive subcontracts to fulfill SBA's procurement obligations. Section 7(j) of the Small Business Act authorizes SBA to provide technical or management assistance to individuals or minority small business concerns.

Participation in the Minority Small Business and Capital Ownership Development Program is open to anyone who can qualify as both socially and economically disadvantaged. Participants eligible by definition include members of racial and ethnic minorities. Other individuals not included by definition may be found eligible upon application to SBA. Criteria for determining social and economic disadvantage are not clearly specified in law or regulations. As a result, program participants are almost exclusively members of the defined minority groups.

PROPOSED LEGISLATION: Congress should amend Section 8(a) of the Small Business Act to include individuals with severe disabilities as a defined minority group for purposes of eligibility in the Minority Small Business and Capital Ownership Development Program. "Disability" would need to be defined in terms of severity, since this term, as used in the Americans with Disabilities Act of 1990, would be inappropriately broad for this purpose. The term "severe disability" must be defined clearly and should include only individuals with one or more of the conditions defined as "severe handicaps" as listed in section 7(15) of the Rehabilitation Act of 1973. The conditions listed include blindness and other severe limitations that are not cosmetic or merely perceived disabilities.

This proposal is simply the recognition of disability as a condition of minority status for participation in SBA'S targeted efforts to provide economic and technical assistance to members of minority groups. The social and economic disadvantages which accompany disabilities are well known and beyond dispute. The problem for SBA has been to define disability and the extent of the class of individuals included. Another problem has been SBA'S lack of legal authority to incorporate such a definition in the absence of a clear legislative mandate. The Americans with Disabilities Act now provides the basis for a legislative mandate, although the definition of disability would need to be more limited.

NEED FOR LEGISLATION: Defined minority status is a distinct advantage in obtaining section 8(a) eligibility. Proof of both social and economic disadvantage can be both time-consuming and expensive. SBA appears to have great discretion in determining eligibility based on social and economic disadvantage, especially for applicants who are members of non-defined minority groups. It is difficult to challenge the decisions made by SBA in this area because the eligibility criteria are so vague.

Firms needing SBA's assistance cannot afford the time and expense of application delays and appeals. In the absence of defined minority status, business failures and bankruptcies can result. This has been the experience of a blind owner of a Tennessee sand and gravel business who is still waiting after seven years for approval of his minority business enterprise application. After finally agreeing that he was both socially and economically disadvantaged, SBA then disapproved his application on the grounds that the business had not been in operation for the past two years. This is only one example of what happens to applicants who are truly disadvantaged but must first prove their minority status before they will even be considered. Congress should resolve this injustice by amending the Small Business Act to include individuals with severe disabilities as a defined minority group.

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Noninvasive glucometers are on the horizon

by Ed Bryant

Because keeping diabetes under control is important in maintaining good health, we diabetics monitor blood glucose levels. To obtain a drop of blood we must puncture a finger. About three years ago, I began hearing about the development of noninvasive glucometers. With such a device, puncturing the fingers two, three or more times daily to obtain blood for glucose readings would become unnecessary.

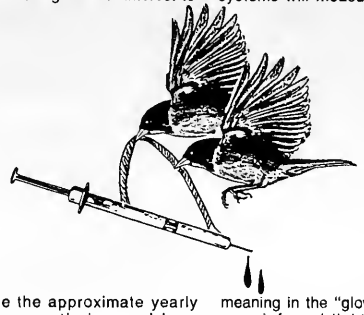
Several companies are striving to develop noninvasive glucose monitoring systems. In April 1992 I conversed with John Forest, Manager of Regulatory Affairs for Futrex Inc. of Gaithersburg, Md. about the "Dream Beam," a noninvasive monitoring system his company is in the process of developing. Forest said it takes a lot of research and time to perfect an instrument of this type. He said that the company hopes to submit the "Dream Beam" to the Food and Drug Administration (FDA) no later than this fall. "Even after the FDA has the device," Forest continued, "it is unknown how long approval or rejection would take."

According to Forest, the "Dream Beam" is portable and can be held in one hand. Using infrared light, it works by inserting the left index finger into the instrument, after which the glucose reading appears on the display window. Forest said the battery powered device is durable and is designed to last several years.

The company has not yet arrived at a price, but Forest said it will be competitive with other glucose monitoring devices currently on the market. He points out that test strips will no longer be necessary and believes that in the long run the "Dream Beam" will cost less than the use of current monitoring systems.

However, I believe the Futrex product may have an extremely high price. Companies will justify the cost by stating the high cost of research and development of a noninvasive glucometer. They will stress that consumers will save money because they no longer need test strips, lancets, lancet devices, and alcohol swabs. For many consumers the biggest selling point will be the fact that finger puncturing will not be required.

I thought it might be of interest to determine the approximate yearly expense currently incurred by a diabetic who tests blood glucose three times each day. The needed items and costs: alcohol swabs, $21 (cotton balls cost considerably less); lancet devices, $14; reagent strips, $750; replacement lancets, $115; glucometer, $150. The estimated yearly cost is $1050 to test three times per day. As to the retail price for the new noninvasive glucometers, I'll leave that up to the imagination of ***Voice*** readers.



I asked John Forest if the company planned to offer the "Dream Beam" with audio output for the many thousands of blind diabetics. He replied, "No, not at this time, but once the instrument has been developed and approved by the FDA, it would be an obvious decision to equip it with voice output." He said that voice output would definitely be an accessory.

Just how does a noninvasive blood glucometer work? In its literature Futrex, Inc. gave an example of shining a flashlight through the palm of the hand. The back of the hand will glow red because concentrated light is being transmitted through the hand. Using a relatively new branch of science called Near Infrared Quantitative Chemical Analysis, noninvasive blood glucose monitoring systems will measure the chemical meaning in the "glow" emitted when near-infrared light is transmitted through an organic object such as a hand. Optical sensors read and transmit the information to a digital readout. Citing the use of the science by the United States Department of Agriculture (USDA) to determine ripeness in fruits, Futrex, Inc. states, "The USDA discovered that if you shine white light [visible light] on an apple, if the light that comes out the opposite side is green in color (remember you can't see it but it can be measured) then without cutting open that apple, you know that apple is sour and hard to eat. If you then shine the white light on another apple, and the white light comes out the other side, you know the apple is not green, and therefore, the apple must be sweet. Moreover, if you test another apple and you shine that light on one side and out comes brown light, you know that the apple is rotten on the inside." Futrex Inc. stated that "light transmittance" is widely used in determining the ripeness and sweetness of fruits and vegetables.

Technology used in space and other sciences goes one step further in using "invisible light" to determine the chemical make-up of a body. Because each element in the universe and their combinations (organic and inorganic compounds) transmit an identifiable signature, sensitive instruments can determine what the element or compound is. In the case of the noninvasive glucometer, the instrument uses near-infrared wavelengths ("invisible light" that can't be seen by the human eye). Although you may not realize it, you are already familiar with such instruments. One device is the television remote control that flashes a beam of near-infrared light to the television, which detects the light and allows the user to select channels, control volume, etc.

Although organic compounds – such as blood glucose – each have their own unique signature which can be measured, Futrex, Inc. explained that one major difficulty in development of a noninvasive glucose measuring device is the fact that the body has such a small amount of blood glucose compared to other body substance. For this reason an especially sensitive device had to be developed. Futrex Inc. literature explained, "... if your blood glucose level is 120 mg/dl, what that number really means is that 0.120% of your total blood (by weight) is glucose. That's a pretty tiny amount, and because it's a pretty tiny amount, the glucose 'optical signature' is very dim and hard to see. This is even more difficult because 99% of the body is a combination of fat, water, and protein that have almost overwhelmingly bright optical signatures. These 'interfering signatures' tend to hide the blood glucose optical signature making it very difficult to measure." However, the company has managed to overcome most of the difficulties and will soon be submitting the instrument to the FDA. How great it will be when the day comes that we diabetics can leave our blood inside the body instead of having to puncture ourselves to measure blood glucose!

Diabetic direction

by Mildred "Barry" Friedman

In 1889 a short (3/4 of a page) paper entitled "Diabetes Mellitus After Extirpation of the Pancreas" was published in the scientific literature. Establishing the fact that the pancreas is involved with the normal carbohydrate metabolism and that its removal causes diabetes, the announcement was a tribute to the importance of being in the right place at the right time.

Authors von Mering and Minkowski met casually one day and discussed von Mering's interest in fat and fatty acid absorption. He had been trying, unsuccessfully, to tie off the ducts of the pancreas in dogs in order to perform fat experiments after the wound healed. Minkowski suggested just taking out the whole pancreas, and volunteered to do the surgery. Von Mering, probably with a smile, agreed and sent Minkowski a dog. Alas – the best laid plans of mice and men ... Von Mering was called out of town for eight days due to an illness in his family. Meanwhile the dog, without its pancreas, began to urinate all over the place and continuously. Minkowski complained to his assistant that the dog had not been trained properly and was told that indeed it had been, and knew how to pee into lab vessels on command. Glucose in this dog's urine was found to be more than 10%, but a glycosuria-producing drug that the animal might have previously taken was blamed.

Critters who did not have sugar in their urine were then pancreatectomized, producing dogs with glycosuria (glucose in the urine), polyuria (frequent urination), intense thirst, ravenous hunger and loss of weight despite good food intake. Diabetic dogs. When blood from a diabetic animal was transfused into a normal animal, glycosuria did not result, but when a piece of pancreas was transplanted under the skin of a diabetic dog, the diabetes disappeared. All these results proved to Minkowski that the pancreas was involved with diabetes.

At odds with this conclusion was the fact that 200 years earlier, in 1682, one Conrad Brunner had pancreatectomized dogs to prove that the duodenal glands named after him functioned exactly like pancreases. His animals withstood the operation and survived for a long time, which suggested that the pancreas was not involved with diabetes.

Then one day Minkowski, wandering at a flea market, noticed a small volume on the corner of bookseller's table. It was by Brunner. On the title page was a representation of his pancreatic operation, which showed that he had not removed the whole gland.

Their monumental 1889 work was published jointly, but as time went by von Mering lost interest in diabetes

(Continued on page 14)

Financing transplantation

by Donovan Cooper

Donovan Cooper (Tom Stevens, at right) is an active member of the NFB Diabetics Division and says that recipients of transplanted organs "are finding ways of paying for their medical expenses and the chances are good that you can too."

From the Editor: Donovan Cooper is a leader in the National Federation of the Blind and serves as the California representative for our Diabetics Division. He is active, productive, and involved in the mainstream.

Donovan's article covers the financing of pancreas-kidney transplantation and has pertinent information for anyone interested. Several centers offer kidney transplants; however, the largest is the University of Minnesota Transplant Center in Minneapolis, MN. For information telephone toll-free 1-800-328-5465.

In the previous edition of the ***Voice of the Diabetic,*** I presented an article entitled "No longer diabetic? Reflections on kidney and pancreas transplantation." In it, I discussed some of my personal experiences and subsequent thoughts on the subject. That article was devoted to the medical and emotional aspects of transplantation. Only in passing did it mention the inevitable financial concerns associated with such medical treatment.

This is not to discount the importance of financial issues when considering transplantation options. The ability to pay may determine whether or not a transplant is possible.

Very few could afford to have a transplant without the support of health insurance. Health insurance as discussed in this article includes both private insurance plans and government programs such as Medicare. Even good insurance doesn't pay for everything. Some commitment of personal resources is required. For example, medical transportation isn't usually covered by insurance. The farther you are from your chosen transplant center, the more costly transportation will be. Fortunately, it is, within certain limitations, a deductible expense on your federal income tax return, and grants may also be available to help finance travel expenses. More on this later.

Transplantation is expensive. To begin with, there is the cost of the pre-transplant workup. If you live in the city where your transplant center is located, you may be able to receive your workup on an outpatient basis. However, if this is not the case, a typical pre-transplant workup will involve about four to five days of hospitalization at the transplant center, where the medical team will conduct perhaps the most complete medical examination you have ever had. It includes an exhaustive series of blood tests, including tissue typing, some high-tech examinations using state-of-the-art medical equipment, and sometimes a heart catheterization. Total costs of these procedures may exceed $10,000.

If the pre-transplant workup reveals any medical conditions that need treatment prior to transplantation, the total costs will include these procedures. For example, if the heart catheterization reveals excessive plaque in the arteries feeding your heart muscle, your surgeon may recommend treatment of this problem before getting a transplant.

You will need to get your teeth cleaned and any other dental work done before you get a transplant. For example, I needed a crown on a molar. My health insurance does not pay for dental procedures, so I had an out-of-pocket cost of $425.

Then there is the transplant itself. Combination transplants such as kidney/pancreas are more costly than either kidney or pancreas transplants alone, but the most expensive option would be to have first one organ transplanted and then, on a separate occasion, the other. If you are a diabetic approaching end-stage renal failure, it may be medically beneficial to have both organs done at the same time and also less expensive.

This is not necessarily to recommend that diabetics should wait until they are at end-stage renal failure before they consider a pancreas transplant. The centers that promote pancreas transplants are in the process of developing data suggesting that the complications of diabetes may be prevented or arrested by receiving a new pancreas. The decision to have a pancreas transplant when it is not combined with a kidney transplant is difficult.

Generally, it comes down to a choice between living with the complications of diabetes or living with consequences of taking immunosuppressant drugs. Neither alternative is ideal, but presently these are the only options, apart from maintaining the best control over diabetes possible.

A typical transplant will require a two–three week stay in the hospital, the use of the operating room and staff, blood transfusions, administration of drugs, daily laboratory tests, and hospital room costs. In addition, there will be bills from the surgeon and the anesthesiologist.

Complications may arise that will require more of the above. These can boost the cost substantially. Insurance coverage may include limits on the amount the company will pay for any one stay in the hospital, so check your insurance contract carefully for such provisions before going for a transplant. Insurance companies set limits on what they will pay for and what they will not. This is true of both public and private programs. Medicare, for example, currently pays for kidney transplants but not pancreas transplants. I am a federal employee who has a variety of group insurance plans available through work. I was using an HMO (Health Maintenance Organization). None of the contracts between the local HMOs and the federal government provided payment for pancreas transplants. Insurance would pay for the new kidney but not the pancreas. However, the federal government's contract with Blue Cross/Blue Shield (BCBS), under its Service Benefit Plan, would pay for both the kidney and pancreas. In order to get both organs transplanted, I had to wait until open season came along when I could change insurance policies and then make arrangements for the combination transplant.

Returning to the subject of post-transplant complications and any related limits on payment imposed by your insurance plan, I am a good example of how one must make prudent choices when considering the coverage available through different insurance plans. When open enrollment came, I examined the two different options available to federal employees through BCBS. It has a standard option and a high option. Both options pay 100 percent of hospital costs after payment of a $50 deductible per stay for the high option, and a $100 deductible per day for the standard option. For me, this was not a significant difference. However, the standard option has a limit of $100,000 per hospital stay, and the high option has no such limit. Being knowledgeable and careful, I chose the high option. It was good that I did. My stay in the hospital was more than twice as long as the average stay. It included three surgeries and treatment for a rejection episode. The hospital bill alone came to more than $129,000.

Following your transplant, there will be aftercare cost. At the very least, this will include post-transplant medications and frequent laboratory tests. It will typically include post-transplant checkups by your transplant center. The University of Minnesota Transplant Center recommends, for persons having had combination kidney/pancreas transplants, a checkup three months after a transplant and then every year thereafter. Each checkup will involve a short hospital stay and, of course, any medical transportation required to get to the hospital and back.

Aftercare costs may also incorporate items such as treatment of post-transplant complications, home health-care nursing until you can care for yourself, and any costs incurred by volunteering for post-transplant medical studies. Many persons experience rejection episodes or infections, such as CMV virus, that necessitate a return to the hospital. The extent to which your insurance plan or plans will cover these expenses must also be considered.

Incidental costs must also be taken into account. You are still going to have other bills while you are in the hospital. Rent, mortgage payments, utilities, insurance premiums, credit card payments, and child-care expenses are among the possible ongoing costs that must be covered while you are in the hospital. If you are not working and have a steady income from a source such as Social Security, then your ability to pay these bills should not be affected by your hospital stay. If you are working and depend on your paycheck and savings, then you will need to plan for your hospital stay by examining the amount of paid leave available and your ability to use savings to pay regular bills in the event that paid leave runs out.

Temporary disability insurance riders for your home mortgage or credit card accounts may also be available. You may also wish to explore the hospital indemnity insurance plans that pay a fixed amount for each day that you are in the hospital. Independent insurance agents are often a good source of information on hospital indemnity plans. Most of these plans have limitations so look them over carefully before investing. Financial planning for transplantation is complex. If you rely on a single medical insurance plan, you will likely find that it does not cover all medical costs.

If you have worked in the past but are not working now due to disability, you may qualify for Social Security disability benefits which also entitle you to Medicare benefits. You may have to wait up to two years after the disability benefits begin before eligibility for standard Medicare becomes effective. There will be no premium for Medicare part A, which covers your hospital expenses, but there will be a monthly premium if you elect to take Medicare part B, which covers doctors' bills, home health care, and prescriptions.

If your work record has not been sufficient to entitle you to Social Security disability benefits, and your income is low, you may qualify for state Medicaid benefits. State Medicaid programs often impose severe limits on the types of services and medications covered. Some medical institutions in your state may not accept Medicaid patients. If you expect to pay for your transplant

through a Medicaid program, then you will first have to find a transplant center in your state that accepts Medicaid patients. If you do qualify for Social Security disability benefits, your monthly payments from this program may be low enough that you still qualify for your state's Medicaid program. Again, Medicaid programs impose limits on covered services, and often these limits are severe.

Whether you are on Medicare, Medicaid, or a combination, your hospital and/or doctor may accept payments from these government programs as payment in full. However, you will still need to pay any Medicare or private insurance deductibles that are applicable. With Medicaid at least, acceptance of Medicaid as payment in full is a requirement. But if you are not eligible for Medicaid, you may need to supplement your Medicare benefits with some private insurance.

Perhaps the best way to accomplish this is to obtain your medical service through an HMO, if you have one available. Whether you use an HMO or another type of private insurance plan, keep in mind that Medicare does not usually work as a supplement to other insurance, but under certain circumstances, private insurance plans will work as supplements to Medicare. When private insurance supplements Medicare, the combined payments from these plans may cover most, if not all, of your medical expenses.

If you are working and have health insurance available through your employer, or if someone in your family is working and you are included in their family health insurance plan, you can avoid paying for some medical costs that your insurance contract does not pay by applying for the Renal Medicare program. Never heard of it? Read on.

The Renal Medicare program is available to people who either are on dialysis or have had a kidney transplant. If you qualify because of dialysis treatments, you can receive benefits from the program for as long as you are on dialysis. If you have a kidney transplant, you can receive benefits from the program for 36 months from the date of your transplant. During the 36 month period if you receive another kidney transplant or go back on dialysis, be sure to contact your Social Security office immediately. They will extend your coverage to meet the new circumstances.

Since Medicare part A is free, and since after a transplant the period of coverage is limited, you should apply for Medicare part A as soon as you go on dialysis or receive a kidney transplant, whichever comes first. However, the decision as to when to make your application for Medicare part B effective or whether it should even be applied for is not that simple. If you have no other health insurance, then you should apply for part B as soon as possible. If however, you have another health insurance policy, then the decision as to when to make your eligibility for part B effective hinges on the date that Medicare becomes the primary rather than the secondary insurance provider. This is one major difference between standard Medicare and the Renal Medicare program. Under standard Medicare, Medicare would always be secondary to any employer-offered private health insurance policy. Under Renal Medicare, the Medicare program eventually becomes primary.

For persons with employer-offered health insurance coverage who also apply for Renal Medicare, your Medicare program will remain secondary to your private insurance for 18 months following your eligibility for Medicare. With a kidney transplant, you become eligible in the month in which you have your transplant. With dialysis, you become eligible three months after you start treatment. If you receive a transplant or are trained in home self-dialysis during the first three months, your eligibility date will be moved forward so that you will still convert to primary coverage under Medicare 19 months after your transplant.

If you belong to an HMO, then don't apply for Medicare part B. You will have to pay part B premiums in addition to HMO premiums, but will receive no additional benefits. Part B premiums will be wasted. If you have other health insurance through an employer and apply for Medicare part B coverage, your application should have its effective date timed so that part B becomes effective in the month in which Medicare becomes primary. Only when Medicare becomes primary will you receive additional payments for part B services. This is because as a secondary provider, your private insurance will supplement the benefits paid by Medicare and you will receive a greater total benefit. Until Medicare becomes primary, your payment of part B premiums will be wasted.

If you have an employer-provided health insurance plan that is not an HMO, then check with your Social Security office to find out in which month your Medicare coverage will become primary, and base the effective date of your part B coverage on that month. If you inadvertently sign up for part B before your Medicare coverage becomes primary, call your Social Security office and request a Refusal Form. Complete the form to withdraw from part B, and submit it to your Social Security office. Once this refusal has been processed, reapply for part B, giving the month in which Medicare becomes primary as the month in which you wish to begin receiving part B benefits. Again, this is based on some assumptions concerning the types of coverage and amounts paid by your private insurance. Medicare part B pays 80 percent of their allowed amounts on covered part B services. If your private insurance plan pays at least 80 percent of the same services and allowed amounts, there will be no additional benefit from Medicare as long as it is the secondary provider.

Then there is the matter of prescription drugs. Unlike standard Medicare, the Renal Medicare program part B pays for 80 percent of your immunosuppressants and other transplant-related drugs for one year after your transplant. Standard Medicare will not pay for these drugs. So, if you are on standard Medicare and have no other health insurance, you will want to switch to Renal Medicare effective with your transplant.

The drug-payment provisions of Renal Medicare are very restrictive. Private insurance is still the answer. HMO plans pay the full cost of prescriptions, usually charging a small fee per prescription filling. Blue Cross/Blue Shield of California and most other BCBS programs offer a mail-order prescription service that pays the full cost for a small prescription fee. Other insurance plans will likely pay at least 80 percent of your prescription costs as long as you are on their plans. This beats the Renal Medicare prescription provisions by a long shot. A social worker at your transplant center can help you apply for the Renal Medicare program if you are not already on the program at the time of your transplant. Once you leave the transplant center, you will need to work directly with your local Social Security office regarding Renal Medicare eligibility issues, applications, refusal forms, and status questions. You will not need to file Medicare claims. Give your health-care providers your Medicare claim number, and they will file the claims.

Private insurance plans (except for HMOs) and Medicare both have deductibles. As a result, each year you will pay the amounts of your deductible as out-of-pocket medical expenses.

Do not forget to include insurance premiums when adding up transplant costs. Prudent choices should be made in consideration of both insurance coverage and related premium costs. This is especially important when considering whether or not to join the Renal Medicare program and when to join it. Remember also that with most newly joined plans, including Renal Medicare, you will have some initial deductibles to pay before your new plans start paying. You should also know that neither your doctor nor the hospital can make you join the Renal Medicare program, but your private insurance plan may or may not require it. Consult with your private insurance provider.

Earlier it was said that medical transportation constitutes a significant out-of-pocket cost that increases the farther you are from your transplant center and your local medical care providers. This is especially true when airplane flights to the center are required. Remember that when donor organs become available, you have only a few hours to get to your chosen transplant center, and you must use whatever transportation mode will get you there on time. Air travel is, therefore, often a consideration.

You will incur travel costs relative to workup, transplant surgery, and aftercare. If you travel by air, this will mean at least two flights and maybe more in less than a year's time. I had three round-trip flights from Los Angeles to Minneapolis during the year of my transplant, and this added substantially to my credit card balances.

Several airlines reduced their fares in April of 1992. Unfortunately, at the same time, they eliminated the discounts previously offered for emergency medical travel. Still, it would be wise to check with your chosen airline to see if any discount options are offered.

There are also grant opportunities. Grant programs vary as to what types of expenses they will cover. For example, the American Kidney Fund has a grant program that helps pay for medical travel expenses and medications related to a kidney transplant. Applications for the American Kidney Fund grants are made through your transplant center's social worker or transplant coordinator. Applications may be submitted three or four times a year. Payments from the fund depend on the fund's current financial status. Reimbursement from the fund, if available, may be delayed for as much as a year. (For more information, call 1-800-638-8299.)

Your transplant center may have other grant programs available to help pay for either medical or incidental expenses. I was recently informed of a patient who received some grant money for child care expenses while in the hospital. Be sure to ask your transplant center's social worker about grant opportunities.

Finally, there is the opportunity for persons with taxable income to deduct a portion of their medical expenses on their itemized tax returns. The IRS will allow deductions for after-insurance out-of-pocket medical expenses, including expenses for doctors, hospitals, prescriptions, medical travel expenses, and health insurance premiums to the extent that they exceed 7 1/2 percent of adjusted gross income (see IRS Publication 17).

As you can see, transplantation is expensive, and the financing is, at best, complex. It is difficult for nearly everyone, and sadly, for some potential transplant recipients there will be some severe limitations on their transplant choices and what they can expect to accomplish. People considering transplants will have to do their own research into what they can afford and how to finance this medical treatment. Careful study, good record keeping, persistence, and patience are all required of both potential and past transplant recipients. But you should take heart. Transplants are being performed all over the country on a great many people each year. Obviously, the recipients of these organs are finding ways to pay their medical expenses, and the chances are good that you can, too.

Titillating word search

Test your skills with our new word search puzzle by Linda Vining. An experienced puzzle constructor, Linda contributes her work to the **Voice** *and has offered to submit more puzzles for your enjoyment.*

Scan the word list containing 28 terms related to diabetes. Search for capitalized words in the puzzle grid. Words read forward, backward, up, down, or diagonally. Indicate located words by circling or marking out. When all 28 words are found, the leftover letters reveal a hidden message which reads from either left to right or top to bottom. The answer grid with circled words and the hidden message appears in the "Food for Thought" column of this issue.

1) CARE
2) CONTROLS
3) DIABETES
4) DIET
5) FBS
6) HEREDITY
7) HIGH count
8) INJECTION
9) INSULIN
10) LEVELS
11) LOW count
12) MEALS
13) MEDS
14) MONITOR
15) ONSET
16) ORAL meds
17) PANCREAS
18) PILLS
19) meal PLAN
20) PUMP
21) injection SITE
22) SUGAR
23) SYRINGE
24) TESTS
25) TREATMENT
26) TYPE
27) URINE
28) WEIGHT

P	T	E	S	N	O	E	E	U	N
P	A	D	N	E	A	G	P	B	O
U	E	N	E	N	N	C	L	Y	I
M	L	T	C	I	O	R	A	L	T
P	I	E	R	R	T	O	N	R	C
S	N	Y	Y	U	E	F	E	B	E
L	S	E	T	E	B	A	I	D	J
O	U	U	I	S	T	R	S	S	N
R	L	W	D	M	E	A	L	S	I
T	I	T	E	I	D	L	E	T	S
N	N	N	R	I	I	O	V	S	U
O	T	N	E	P	G	W	E	E	G
C	S	U	H	I	G	H	L	T	A
G	A	R	M	O	N	I	T	O	R

Diabetic direction

(Continued from page 11)

and Minkowski, who had been 31 years old when he did these experiments, went on to devote the rest of his life to pancreatic diabetes.

In the last century, NIDDM (Type II or Non-Insulin-Dependent Diabetes Mellitus) was rarely reported in native Americans. Since 1940, very high rates of incidence have developed among some tribes, notably the Pimas (with one of the highest rates in the world – approximately 50% of adults), Papagos, Yumas, and Comanches. Athapascans, Aleuts, Eskimos, Navajo and some Apaches comprise a group which also suffers from NIDDM but at a lower rate. What has caused this increase? Current thought is that interaction between their genes and changes in lifestyle are to blame. Wendorf and Goldfine have published intriguing thoughts concerning the archaeology of the Indian genotypes.

The diabetic gene is referred to as the "thrifty" gene because it causes accumulation of fat when caloric intake is high and slow metabolism of stored fat when few calories are consumed. Survival in a feast or famine regimen is the result. Thousands of years ago people moved across the land connection from Asia and began to travel south down the Americas. Some of them remained in the northern regions and some continued south. In the north many animal species live in large groups and the people lived near these herds, migrating with them and securing for themselves a constant source of food. In warmer climates there tend to be more species but fewer animals of each kind. Humans are inclined to live in permanent camps and go on hunting expeditions, thus generating a feast-famine eating pattern. Thrifty genes would help them survive. Today's high incidence NIDDM tribes are the descendants of southern people. New eating habits mix with inheritance and produce fat diabetic Indians. Interestingly, spiny mice and Egyptian sand rats, both desert animals, become fat and diabetic when given a constant source of food.

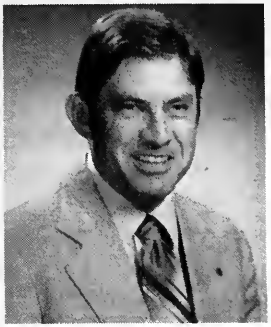
Type II diabetics are joined by other diabetics in a mutual suffering from overweight. Wisconsin diabetics were studied by Wing and Moss, and their conclusions are probably true for patients living in different areas. They found that IDDM (Type I or Insulin Dependent Diabetes Mellitus) diabetics under good glucose control tended to gain more weight than poorly controlled ones. Of the 405 people followed for four years, the one-fourth who showed best glycemic control gained 3.4 kg (12% became clinically obese) while the worst controlled one-fourth lost 0.6 kg (3% became clinically obese). That weight gain is an adverse effect of improved glucose levels is supported by the findings of the DCCT (Diabetes Control and Complications Trial) which showed the same thing. Intensive therapy may make people feel freer to eat more, may increase appetite, or change the metabolic rate. We are told that maintenance of near normal sugar levels possibly leads to avoidance of diabetic complications. However, there will be more of each of us to keep uncomplicated. What's the opposite of "every dark cloud has a silver lining"?

Speaking of the DCCT, which is a long-term attempt using many Type I diabetics, at many centers, to prove the connection between glucose control and the appearance of diabetic complications, there is a secondary finding which intrigues me. Compliance. Over 95% of the participants do what is expected of them. Self-monitoring, recording results, taking medications, appearing for appointments, following diets – all are conformed with. Why? Truth is that these patients were specially selected. Bad risks, such as those who had frequent hypoglycemia or suffered from advanced complications, were excluded. The only other time I have read about such compliance concerned pregnant diabetics who wanted normal babies. They worked at it. Both groups shared one thing – much attention from the health care providers they were involved with. Maybe we should learn that good medical care demands individualized concern, possibly given in a directed, defined manner.

(Note: This article appeared in the Volume 6, Number 2 issue of *Renalife,* published by the American Association of Kidney Patients, reprinted with permission from the author.)

Ask Dr. James

by Ronald James, M.D.



Ronald James, M.D., long-term insulin-dependent diabetic, directs Midwest Diabetes Treatment and Education Center, Columbia, Mo. Dr. James is also the Medical Director of the Central Missouri Diabetic Children's Camp, Inc.

(Note: if you have any questions for Dr. James, please send them to the editor. The only questions Dr. James will be able to answer are the ones used in his column.)

How does alcohol affect diabetes? Should I abstain from all alcoholic beverages, or are there a few I can drink in moderation?

Alcohol, as such, decreases blood glucose by inhibiting glucose production by the liver. This effect is prolonged, often lasting for several hours. On the other hand, alcohol is consumed as beverages that frequently contain variable amounts of carbohydrates, often in the form of sugars. Of course, the carbohydrates tend to raise the blood glucose. Therefore, alcoholic beverages tend to cause wide swings in the blood glucose levels, often raising them at or shortly after the time of consumption and later causing them to fall. If one has an insulin reaction with alcohol present, the normal response of the liver to produce glucose is inhibited. This may make the insulin reaction worse.

Of course, excessive consumption of alcohol will make the diabetic drunk, as it will anyone. Under such conditions, the diabetic's behavior may be less than optimal, resulting in not following the treatment program. Failure to take one's medication, particularly insulin, may result in diabetic ketoacidosis which could be fatal. Failure to follow the diet may result in insulin reactions. If one with the odor of alcoholic beverages on the breath should black out from an insulin reaction and be found by the police, they may take him/her to jail assuming he/she is drunk. This would not be appropriate treatment for an insulin reaction.

In my opinion, it is best to abstain from the use of all alcoholic beverages. However, if one feels he/she is unable to do this, certain rules may be helpful: 1) Use alcoholic beverages with as little carbohydrate, especially sugars, as possible. For example, use dry instead of sweet wines, use mixed drinks that contain little or no sugar such as many containing vodka, or use a sugar-free alcoholic beverage "on the rocks." 2) Drink in moderation and do not get drunk. 3) Otherwise, always follow one's usual treatment program including diet – do not skip food. 4) When drinking, always be sure there is another responsible person around who would be able to summon help in case of illness or unresponsiveness.

What should I use to stop an insulin reaction? I've heard that table sugar works well.

The purpose of treating an insulin reaction is to raise the blood glucose up to normal within a reasonably short period of time. This usually can be done best by taking sugar in some form. Glucose, the sugar in our blood, acts the fastest because it is readily absorbed from the intestinal tract and does not require digestion or other changes. It is available in powder form, which many do not like, as large glucose tablets which can be chewed and swallowed, and as concentrated jell preparations. Table sugar also works well. It can be taken dry, dissolved in a liquid such as juice, or in the form of sweets such as candy, pastries, or sweet soft drinks. It requires digestion, which converts it to equal amounts of glucose and another sugar, fructose. Although it does not act quite as fast as glucose itself, table sugar works well and is relatively cheap, costing only two or three cents per reaction.

Although starches or protein containing foods will eventually treat an insulin reaction, digestion and other changes necessary to produce glucose requiring considerable time generally make these foods a poor choice.

Why does my eyesight get blurry or fuzzy when my blood sugar is too low or too high?

As one's blood sugar (glucose) rises and falls, the glucose content of the eye also tends to vary up and down. This affects the front of the eye, including the lens, which has to do with focusing images of what one sees on the retina in the back of the eye. As the glucose goes up and down, the amount the lens bends the light rays changes. When the light rays are bent so they do not focus on the retina, blurred vision results.

During an insulin reaction, when the blood glucose is low, the body tries to correct it by producing adrenalin. This substance, also called epinephrine, is produced by the adrenal glands and stimulates the liver to make glucose, thus bringing the blood glucose level back up. In addition, adrenalin causes one's pupils to dilate. This may result in blurred vision during an insulin reaction.

Exercise quiz

by Tim E. Rickabaugh, MA
Tim Rickabaugh is an exercise physiologist at the St. Vincent Diabetes Center in Indianapolis, Indiana.

TRUE OR FALSE
(Circle T or F and then go to conclusion of quiz for answers.)

1) I do not need to carry any simple carbohydrate with me when I exercise, if I don't take any diabetes medication (insulin or oral agent). T F

2) It is a good idea for me to exercise when my blood glucose levels are greater than 250 mg/dL, because I can then "burn off" the extra blood glucose. T F

3) I should discuss my exercise plans with my physician because I have diabetes, even if I don't have any other health problems. T F

4) I should wait 1 1/2 hours after a meal before I start an exercise session. T F

5) If my blood glucose levels are 66 mg/dL before I start to exercise, I should make my exercise session shorter than usual (half of my normal duration). T F

6) I should check my blood glucose levels immediately before exercising to see if I need a pre-exercise snack. T F

7) Tennis is one of the best types of aerobic exercise. T F

8) I should avoid exercising in the three-hour period before bedtime. T F

9) If I exercise regularly, my body will respond by producing more insulin, and this will lower my blood glucose levels. T F

10) I should slowly increase the duration (minutes) of my aerobic exercise until I am able to do 20 to 60 minutes of continuous exercise. T F

EXERCISE QUIZ ANSWERS ON PAGE 20

Ask the experts

Question: I understand that there is some work being done on pumps that can be implanted in the body to release insulin. Is this something that will be successful and are we likely to see this in the near future?

Answer: As you probably know, we now use external insulin pumps with a significant degree of success. The external pump is a small device that I would describe as being smaller than a standard deck of cards which can be worn on the belt or hidden in clothing. This pump has an insulin delivery system in it with a tube that is connected to a needle placed under the skin. The pump delivers insulin 24 hours a day and boluses in extra insulin for meals. The pump has a lot of advantages in that it maintains insulin levels throughout the day like the normal pancreas as well as allowing the delivery of insulin at mealtime. The pumps have had somewhat limited use but have proven to be a highly effective way of managing diabetes.

There have been ongoing research projects for at least the last twenty years looking at an implantable pump. There are now at least two major companies that are moving into the final phases of internal pump development. It looks quite promising that these will be generally available within the next year or so, but I do not have an absolute deadline. These pumps work by placing the pump under the skin. They are about the size of a hockey puck and are managed somewhat similarly to a pacemaker placement. The pump will have insulin and deliver it through a system which is all entirely beneath the skin. Some of these systems use a highly concentrated insulin so that only a small volume of insulin is required. The pumps need to be refilled every few months, and apparently will be able to be filled without any sort of major discomfort or additional operation. These pumps look promising and I am hopeful that they will prove to be of benefit.

(*Note:* This article appeared in the 1991 Fall issue of the *South Dakota Dialogue*, published by the ADA South Dakota Affiliate, Inc.)

What do you need to know about your illness?

by Mark Flapan, Ph.D.

(Editor's Note: Although diabetes is not a rare disorder, the information contained in this article may be helpful. Education is essential. This story appeared in Volume 9, Edition 3 of *Orphan Disease Update,* published by the National Organization for Rare Disorders, Inc. Reprinted with permission.)

Are you the kind of person who wants to know everything you can about your illness or would you rather not know any more than necessary? It's generally assumed that the more you know the better. You're encouraged to ask your doctor questions, to read all you can about your disease and to attend meetings related to your illness. If you're not interested in becoming such an "informed patient" you may be accused of "denying your illness."

What you know or don't know about your illness not only affects how you take care of yourself *physically,* but how you live with yourself *emotionally.* What you know depends on what you *want* to know, which may be *more* or *less* than you *need* to know for your physical and emotional well-being. What you want to know, in turn, depends on the kind of person you are and how you deal with your illness.

It's important for you and those close to you to understand and respect your desire "to know" or "not to know" since these are fundamental to your way of being. But it's also important for you to understand yourself well enough to determine whether your desire to know or not know is in your best interest *physically* and *emotionally.*

You want to know everything you can

You may be the kind of person who wants to know everything possible about your illness. No matter how much your doctor tells you, it's never enough. This is especially so if you have a doctor who tells you very little. In any case, you realize you can only learn so much from your doctor, so you read everything you can get your hands on, attend meetings where doctors give talks about your disease and talk to others who have the same illness as you do. When you first learned you had a chronic illness, you couldn't believe you had it – certainly there had to be some mistake. So you read up on the disease to see for yourself whether you actually had what the doctor said you had – hoping, of course, you didn't.

When you finally accepted the fact that you did, indeed, have a chronic illness you couldn't believe there was no cure. There had to be a cure somewhere, so again you decided to look into the matter yourself. You called people and tried to find out what you could about whatever research was going on and about any experimental treatments. You even tried to find out if there were drugs for your illness in Europe not approved for use in the United States. You left no stone unturned trying to find a cure – nutrition, vitamins, acupuncture, relaxation techniques – you name it, you looked into it.

To this day you try to find out all you can about available treatments so you'll know you're getting the best treatment possible. You don't want to depend only on your doctor for this. You want to keep up with ongoing research to learn if a cure is on the horizon. You attend meetings about your illness – hoping to hear of some new treatment. You don't want to miss out on anything that could help you.

If you're a person who doesn't like to take drugs, you may need to know the possible side effects of suggested medication. You look these up yourself, just to make sure the effects of the treatment aren't worse than the disease.

You also talk to others who have the same illness. You want to find out if they have symptoms similar to yours and how your symptoms compare to theirs. You want to find out how much worse your symptoms can get and if they ever get better. You also want to learn what medications others are taking and what else they're doing for themselves.

But what's the value of knowing so much?

Needless to say, knowledge about your disease evokes fears of symptoms and complications you may never get. You were certainly frightened reading about your disease in medical books and you were upset by seeing slides doctors showed at meetings you attended. It's impossible to learn what might happen in your disease without imagining it *will* happen to you. It's still more frightening to learn what's happening in your own body. Even when your doctor doesn't say anything upsetting, you start to worry if, after he's examined you, you sense he's concerned about something. You were shaken when he told you about a new development. You not only had something new to worry about, you had something new to find out about. But even if it upsets you, you still want your doctor to tell you everything.

So what's the point of knowing so much? A greater understanding of your body and your disease enables you to ask more sensible questions of your doctor and to more easily understand and remember what he tells you. The more you understand how your body is supposed to work, the better you're able to report physical changes that are relevant, and the less troubled you are by changes that may have no consequence. The way you see it, what you know and say to your doctor makes a difference in the kind of medical care you get.

Also, you don't like having to rely completely on your doctor's remembering everything related to your "case". He has many patients to keep in mind, and even with his notes in your medical record, he may forget some aspects of your condition or treatment. As it happens, you have only one person to keep track of – you – and you feel more secure when you keep your eye on things yourself.

It's upsetting to have strange things happening to your body with little understanding of what's going on. But regardless of how much you know about your symptoms, it's still distressing to feel and see your body changing before your eyes. But somehow, it's a little easier to come to terms with changes in your body if they're not so mysterious.

Knowledge about your illness, and how it's affecting you, lessens your feeling of helplessness and enables you to feel more in control over what might happen. Although greater knowledge may not, in fact, give you this control, it relieves some of the apprehension related to the "unknown." You would rather come to terms with the worst, whatever it might be, than live in the dark – not knowing what might happen. So even if you're upset, frightened or depressed by what you learn, there are many reasons you want to know everything you can about your disease. You just wish your whole life didn't revolve around your illness. Sometimes you feel you're so taken up with your physical condition that nothing else in the world matters. It's hard not to be preoccupied with yourself when scary things are happening to your body. But at other times, you wish you could get on with your life so you wouldn't miss out on so much.

You want to know only what you have to know

You may, on the other hand, be the kind of person who doesn't want to know any more than is absolutely necessary about your illness. Even before your illness, if you heard about some medical disorder, you became frightened you would get it. You know your imagination would run wild if you knew too many specifics about your disease.

For you, coping with your illness depends on remaining as hopeful and optimistic as possible. You want to maintain a positive attitude and for you "not knowing" helps. You prefer to deal with developments as they come along, rather than worry about everything that might happen. After all, none of these things may ever happen to you, so why do you need to know about them?

What can you do with more knowledge about your condition anyway? Knowing about the intricacies of the disease won't make it go away. So what's the point of knowing more than you have to, when it only frightens and upsets you?

So, to keep from getting frightened or depressed, you don't want to read about your illness or listen to doctors talk at meetings about the disease. And you don't want to meet others with the same illness and get upset by seeing their symptoms or hearing the details of what's happening to them. In general, you would just as soon not think about your illness any more than necessary – it's on your mind enough already, so why dwell on it?

As a child, when you were sick, you were comforted by a caring mother and treated medically by the family doctor. Now that you have a chronic illness, you still wish you had a mother to comfort you, whatever your age. And you certainly want a concerned doctor to take care of you.

Although you feel secure relying on your doctor to tell you whatever you need to know, you prefer he not tell you too much. The doctor who diagnosed your condition may have scared you to death by telling you all the things that could happen. Maybe you were so unfortunate as to have a doctor tell you how many years you had to live – and you believed him. This "knowledge" threw you into such despair you gave up before you got started.

Since then, you've learned such predictions aren't the last word. But his words still linger on in your mind – unless, of course, you've already outlived his dire prediction.

While you depend on your doctor to take care of you, you don't want to see him any more than necessary. You may go so far as to avoid mentioning some new symptom to your family, because they would insist you make an appointment, and you're afraid your worst fears will be confirmed.

You even ignore new symptoms or try not to notice old symptoms getting worse. You're hoping nothing is seriously wrong, or if something is, it will go away by itself. You know you shouldn't put off medical attention by ignoring what's going on, but you do it anyway – you're so afraid of what you might find out.

When you do finally see your doctor, you don't ask too many questions for fear of becoming upset by what he tells you. So a family member sometimes comes along to ask whatever you may need to know.

Your security comes from faith in a knowledgeable and concerned doctor who's in charge of your medical care,

(Continued on page 18)

Ann Terry is a registered dietitian who works at the State Hospital in Fulton, Missouri and at the Veterans Administration Hospital of Columbia, Missouri. She graciously calculates the diabetic exchanges and food values for our recipes.

Send your great ideas to the editor. He is the official taste tester and needs recipes to test his taster.

Pork Tenderloin Diane

Anonymous

1 lb. pork tenderloin cut into 8 crosswise pieces
2 tsp. lemon pepper
2 tbsp. butter
2 tbsp. lemon juice
1 tbsp. Dijon-style mustard
1 tbsp. minced parsley or chives
2 tbsp. Worchestershire sauce

Place each piece of tenderloin between two pieces of plastic wrap. Flatten slightly with heel of hand. Sprinkle surfaces of medallions with lemon pepper. Heat butter in heavy skillet, cook tenderloin medallions three to four minutes on each side. Remove medallions to serving platter, keep warm. Add lemon juice, Worcestershire sauce, and mustard to skillet. Cook, stirring with pan juices, until heated through. Pour sauce over medallions, sprinkle with parsley and serve.

Yield: 4 servings. Calories: 188. Diabetic Exchanges: 3 lean meat.

Summer Squash

(Note: This recipe appeared Wednesday, October 30, 1991 in the *Argus Leader,* Sioux Falls, SD.)

1 summer squash peeled and cut into pieces (2 cups)
2 tsp. cinnamon
Dash nutmeg
Brown sugar substitute
1/2 cup water

Peel and cut squash into pieces. Lay them into a Corning ware dish that has been sprayed with Pam. Mix cinnamon, nutmeg, and brown sugar substitute together and sprinkle over the squash. Add water, cover and bake at 350° until tender.

Yield: 2 servings. Calories: 25. Diabetic Exchanges: 1 vegetable.

(Editor's Note: The following sweet treats were adapted from recipes used by dietitians at Lookout Mountain Hospital, Spearfish, South Dakota.)

Dried Fruit Bars

1 cup dates (chopped)
1/2 cup raisins
1/2 cup prunes (chopped)
1 cup water
1/2 cup margarine, softened
2 eggs
1 tsp. baking soda
1 tsp. vanilla
1/4 tsp. salt
1 cup flour
1/2 cup pecans (chopped)

Cook dates, raisins and prunes in water for five minutes. Set aside to cool. Cream margarine and eggs together. Add to cooled fruit mixture. Combine baking soda, vanilla, salt, flour and chopped nuts. Add to fruit mixture. Pour into a greased 9x13 pan. Bake 25-30 minutes at 350 degrees. Cool and cut into bars.

Yield: 18 servings (serving size - 1 bar). Calories: 160. Diabetic Exchanges: 1 fruit, 1 fat, and 1 bread.

Cheesy Barbecue Popcorn

3 tbsp. margarine
1/2 tsp. chili powder
1/2 tsp. garlic salt
1/4 tsp. onion powder
8 cups popped popcorn
1/2 cup grated Parmesan cheese

Melt margarine; add seasonings. Pour over air-popped popcorn. Sprinkle cheese over top and mix thoroughly. (Note: To lower sodium content, substitute 1/4 tsp. garlic powder for the garlic salt.)

Yield: 4 (2 cup) servings. Calories: 165. Diabetic Exchanges: 1 bread, 1 fat, and 1/2 meat.

Honey as a sweetener?

Honey was man's first important concentrated sweetener. Because of its "naturalness", long history, and trace amounts of nutrients, some people have suggested that it is a good sweetener choice for diabetics. It is **NOT.** Honey's large amounts of glucose make it as bad as regular table sugar for people who have diabetes. To get any benefit from the small amounts of nutrients in honey, you would have to eat very large quantities. You would probably be getting those nutrients anyway from other foods you eat that are much lower in calories.

You may find honey listed as an ingredient on a food label. Foods with small amounts of honey can be figured into the diabetic diet. For example, graham crackers which may include honey are counted as a bread exchange. (If honey is listed first or second on the list of ingredients it will be in greater quantity than if it were listed last.)

(*Note:* This article was written and submitted by Claire Hammer, R.D. It originally appeared in *Dealing with Diabetes*, a newsletter for diabetics in prison.)

Hopkins nurse says surgical pain mishandled

News release from Johns Hopkins Medical Institution.

Half of all patients suffer unnecessary pain following surgery as a result of too little or inappropriate medications, according to findings of a new federal study released February 3, 1992. Such unrelieved pain can result in slower recuperation, serious medical complications and prolonged hospital stays, the results suggest.

In response to these findings, a federally mandated panel on pain management today issued a lengthy set of guidelines supported by Health and Human Services Secretary Louis W. Sullivan, M.D. They are expected to have long-range effects on pain management in hospitals throughout the country.

The guidelines urge aggressive control of pain before, during, and after surgery and stress the importance of frequent reassessment and recording of patients' pain. In addition, they recommend discussion options for treating pain with patients and paying close attention to patients' preferences in alleviating pain.

The federal panel, convened in 1990, is co-chaired by Ada K. Jacox, Ph.D., R.N., Independence Foundation Professor of Nursing at The Johns Hopkins University School of Nursing in Baltimore, and Daniel Carr, M.D., director of the division of pain management of the Department of Anesthesia at Massachusetts General Hospital in Boston. Fifteen other health-care experts also were on the panel, including nurses, physicians, an ethicist, a pharmacist, a psychologist, a physical therapist and a consumer who has undergone multiple surgeries.

With approximately one half of all surgical patients experiencing moderate to severe pain following surgery, the importance of pain management cannot be underestimated, Jacox says. "For 30 years, these statistics have been the same. We now know that many of these episodes can be entirely prevented by adherence to an aggressive program of pain control," she added.

One of the panel's potentially controversial recommendations is that morphine be used as the drug of choice following surgery, and that meperidine, known widely by its trade name Demerol, not be used except when patients show an intolerance to morphine.

"The problem with meperidine," says Jacox, "is that its side effects can be severe, and doctors have a tendency to underprescribe it. The result is more pain – and thus a slower recovery – for the patient."

Jacox noted that the panel's guidelines indicate a changing philosophy toward pain. In the past, she said, postoperative pain was viewed as inevitable, to be tolerated stoically. "It is now clear," she adds, "that incompletely treated pain can slow recuperation or even provoke complications such as pneumonia, heart attacks, or blood clots."

The potential for financial savings from avoiding these long-term complications is profound, according to the panel. Said Co-Chairman Carr, "If one assumed a hospital stay shortened by even a half-day in just 50 percent of the 23 million operations performed outside of federal facilities each year, that would mean savings in the billions of dollars."

The panel recommends doctors and nurses discuss various types of opioid analgesics that can be used, dosage and dosage schedules, and non-drug techniques of reducing pain, such as relaxation and patient education. Inherent in all the guidelines is the idea that timing is essential, especially during the first 24 to 48 hours following surgery, when medication generally should be given around-the-clock rather than on an "as-needed" basis.

An additional element of the program, but one without immediate financial effects, is that patient satisfaction is significantly higher during aggressive analgesia rather than conventional treatment. "Hospitals that ignore the importance of patient satisfaction," says Jacox, "may find themselves with decreasing numbers of patients to care for."

According to Jacox, the panel's conclusions will have profound implications for hospitals, which are being asked to implement formal means to assess and control patients' pain. The panel stressed the importance of having a pain management program within each hospital run by the physicians and nurses most knowledgeable about pain control.

The guidelines introduced today also are expected to be used by the courts in malpractice cases. According to Jacox and Carr, judges may use the guidelines along with other evidence to determine whether the professional judgment used in a particular situation was appropriate.

The guidelines, which were sponsored by a branch of the Agency for Health Care Policy and Research (AHCPR), will be distributed to physicians, nurses, medical and nursing societies, health professions schools, insurers, consumer groups and others. According to Jacox and Carr, their findings will be reviewed and updated periodically, as needed. "Our goal," said Jacox, "has been to help physicians and other health professionals provide the best possible patient care; we believe their implementation will mean greatly alleviated pain for patients as well as greatly reduced health care costs for everyone."

Copies of the AHCPR guidelines, titled *Acute Pain Management: Operative or Medical Procedures and Trauma,* quick reference guides for postoperative pain and the patient's guide are available without cost from the AHCPR Publications Clearinghouse, P.O. Box 8547, Silver Spring, MD 20907; telephone: 1-800-358-9295.

What you always wanted to know but didn't know where to ask

(Resource list)

(Inclusion of materials in this publication is for information only and does not imply endorsement by the Diabetics Division of the NFB.)

New Glucose Monitoring System
by Ed Bryant

The Diascan Partner with voice output was unveiled at the National Federation of the Blind annual convention in Charlotte, North Carolina, June 28 through July 4, 1992. I have seen and "played" with a prototype of the new blood glucose meter with audio output and it is great.

The new system is housed in one small eight ounce unit. The voice can be set for desired volume and is easy to understand. The system is user friendly and will announce the calibration setting and allow it to be changed if needed. You don't need to get a drop of blood on the center of a reagent strip pad. Blood can be smeared onto the pad and still obtain an acceptable clinical reading.

I am told that the Diascan Partner will be available for purchase sometime in August 1992. The suggested retail selling cost is $399. This means that the Diascan Partner is, by far, the most economical talking glucometer sold in the United States. It comes with cassette and print instructions. A sample tape is offered free upon request. Contact: Home Diagnostics, Inc., 51 James Way, Eatontown, NJ 07724; telephone toll free: 1-800-342-7226; or call: 908-542-7788.

Speech Synthesizer

Aicom Accent Text-To-Speech Synthesizer: Converts text on your computer screen to speech, with vocabulary of over 20,000 words. Six models: full-length ($745) or half-length ($545) PC plug-in cards for IBM PC-compatibles; cards for Toshiba laptops T1200, T1600 ($395) or T1000SE ($625); plug-in card for Microchannel PS/2 ($745) or stand alone unit with RS-232C link to any computer ($995); plug-in card for Toshiba T1200XE, T2000SX Laptop plug-in card ($675). Supported by all major screen reader programs. Contact: Aicom Corp., 1590 Oakland Road, Suite B112, San Jose, CA 95131; telephone: (408) 453-8251; fax: (408) 453-8255.

The Rooster

The Voicer Talking Watch is available for a limited time. This watch features a "rooster" alarm, hourly announcement and a 1/4 visual display.

The Voicer costs $15.00 each (#AIB18T). Order from (send check or money order): The National Federation of the Blind, Materials Center, 1800 Johnson Street, Baltimore, MD 21230; telephone: (410) 659-9314.

Aids and Appliances

The ***Voice of the Diabetic*** reaches thousands of newly blinded men and women who often aren't aware of available resources. The National Federation of the Blind (NFB), with more than 50,000 members, is the largest organization of blind people in existence.

The NFB has a materials center which houses thousands of products. A wide variety of items are available, such as: white canes and accessories, Braille and print writing supplies, Braille watches, talking clocks and calculators, cassette players/recorders, measuring devices, housewares and games.

An aids and appliances descriptive order form is available in Braille (LBA04B) and/or print (LBA04P). Please order free copies from the National Federation of the Blind, Materials Center, 1800 Johnson St., Baltimore, MD, 21230; phone: (410) 659-9314.

Talking Blood Pressure Meter

Cardio-Vox™ Talking Blood Pressure Meter: This new blood pressure cuff announces systolic and diastolic pressure, pulse rate, time and date, and stored readings. The arm cuff automatically inflates and deflates. Blood pressure results may be printed out with time and date. Four "AA" batteries are included.

Operating buttons are in print and Braille. It comes with cassette instructions and a large print manual. Order #N90990; cost: $199.95 plus $7.50 shipping. Order from: American Foundation for the Blind, Inc., 15 West 16th Street, New York, NY 10011; telephone: 1-800-829-0500.

Literature

Convenience Food Facts: Help for the Healthy Meal Planner by Arlene Monk and Marion J. Franz reviews nutritious quick packaged foods from complete dinners to snacks. It includes listing of 1500 popular brand name products with nutritional breakdown, easy to follow charts and revised exchange values. Cost: $10.95, plus $2.50 shipping. Order from the International Diabetes Center, Minneapolis, Minnesota; outside Minnesota: 1-800-848-2793; in Minnesota: 1-800-848-5951.

Month of Meals by the ADA provides diabetics with information about planning meals for the calories and exchanges of individual diets. A charted table tells how to plan meals. Cost: $13.00. Order from the American Diabetes Association, Alexandria, VA; telephone: 1-800-232-3472, extension 363.

What do you need to know about your illness?

(Continued from page 16)

and who will do whatever has to be done. You're most comfortable relying on his knowledge and putting yourself in his hands rather than having to know it all yourself. When a new treatment comes along, he'll certainly hear about it, and will let you know if it can be of any help to you. That's what you have a doctor for, isn't it?

So what do you need to know?

Whether you would like to know as much as possible about your illness or don't want to know any more than necessary, it's important to be able to do the things you have to do to take care of yourself. You've probably read or been told by your doctor how much rest and exercise to get; what foods, if any to avoid; whether or not vitamins can help; when to take your medications before, after or between meals; and what to do if you forget to take them, and there may be many practical suggestions about how to "manage" your disease. For your best physical care it's important to know about these.

Knowing more is up to you

How much more you actually *need* to know about your disease is more *emotionally* than *physically* relevant. What best enables **you**, particularly, to cope with your illness depends upon how you react to crises, and a chronic illness is a series of crises.

You may be neither the kind of person who wants to know everything nor the kind who wants to know only what's necessary. You may be somewhere in between. What's more, your desire to know may change through time. If, at first, you wanted to know everything possible, your desires to know more may lessen as you sense that with or without your knowledge, your disease has a life of its own. On the other hand, if at first you wanted to know as little as possible, you may become more comfortable learning more, as you're increasingly able to face the reality of your illness.

But if new symptoms suddenly emerge, your desire to learn all you can about what's happening or your inclination to rely only on your doctor to tell you what you need to know is likely to re-emerge. Wanting to know everything or wanting to know only what is absolutely necessary are both ways of coping with fear. And the progression of your disease certainly evokes fear.

In any case, the kind of person you are and your characteristic way of coping with fear are not likely to change dramatically because you have a chronic illness. And as I said before, you, as well as those close to you, need to understand and respect the way you are. However, it's also up to you to understand yourself well enough to decide how much you *should know* for both your *physical* care and your *emotional well-being.* When all is said and done, who can decide this better than you?

Dr. Mark Flapan has scleroderma and is president of the Scleroderma Society. He is a psychologist in New York City and has a special interest in the emotional effects of chronic illness both on the ill person and on family members.

Food for thought

Support and Information

From the Editor: This letter to Ken and Linda Carstens shows how valuable our Diabetics Division network is. We provide support and information to anyone interested. Ken Carstens cochairs our Amputation and Prevention Committee. He is a long-term diabetic who is always willing to assist individuals. The letter's author, Ms. Schroeder, gave us permission to reprint this note of appreciation. She is a member of a diabetic support group which the Carstens help coordinate in Virginia, Minnesota.

Dear Ken and Linda,

I just wanted to take this time to say special thanks to both of you for being just exactly what you are. You sure make a fine team.

When I was first diagnosed to have diabetes, of course it was completely out of control. I was losing my sight and scared to death plus feeling very sick and depressed. The doctor just shoved some diabetes pills at me to be taken three times a day and dismissed me. A friend of mine picked up a copy of ***Voice of the Diabetic*** at the clinic since he had been told he had a very high sugar count. He passed the paper on to me.

I called Ed Bryant since I got his name from that paper. I got on the mailing list for the paper, plus was given your names as valuable people for giving information in this area. Because of your encouragement, I have a new and healthy outlook on life. I know others with much bigger problems are moving along just fine. There is no good reason for me to sit here and have a pity party.

The diabetic support group is very helpful, too. I appreciate your getting such good speakers. It indeed opens our eyes to so many areas not thought of as having connections to diabetes. One man's opinion was: All old people get diabetes to some degree. It's nothing to worry about. No one ever died from it!

Love,
Blanch Schroeder

Weigh it Down

We received a tip from Don Andrews of Williamsburg, Virginia.

The disks, or flimsy records, that blind patrons receive from the Library of Congress often slip on the turntable, making them hard to understand. If you put about three quarters, nickels, or even washers in the center of the record, it will weigh it down to prevent this slipping.

Thanks, Don, for the tip.

Karen Mayry, President, NFB Diabetics Division, wins prestigious award as Volunteer of the Year.

President Wins Award

Karen Mayry, President of our Diabetics Division, received an award of one thousand dollars as the 1991 South Dakota Volunteer of the Year. She was recognized for her contribution in helping blind persons, as well as diabetics facing complications. This prestigious award is well deserved.

Lutheran Braille Workers

We have been asked to announce the following: The Lutheran Braille Workers offers Braille and large print material to the blind and visually handicapped. Braille material is formatted in grades one and a half and two.

Various books of the Bible are available in the New International Version as well as other religious material. Selected readings are also offered in other languages. Limited quantities are available.

To obtain a list of materials contact: Lutheran Braille Workers, P.O. Box 5000, Yucaipa, CA 92399; telephone: (714) 795-8977.

Herbal Food Interest

An insulin-dependent diabetic of 29 years wishes to communicate with other ***Voice*** readers about the general use of herbal foods in the diabetic diet. This reader is particularly interested in the "Sunrider" brand and how other diabetics who take insulin have used this product line. To communicate, contact Mary C. Campbell, P.O. Box 155, Breckenridge, CO 80424; phone: (303) 453-2231.

Do You Know?

The following humor is from Linda Vining of Aberdeen, SD. She claims that these rules, depending on how you look at it, explain some things.

Marriage is the only union that can not be organized. Both sides think they are management.

If you do not want your children to hear you, pretend that you are speaking to them.

If it were not for the last minute, nothing would get done.

I got a dog for my boyfriend ... it was a fair trade.

The Store

We have been asked to announce the following: the Massachusetts Association for the Blind has a new 1992-94 catalog for The Store, which sells products for blind and visually impaired individuals. There are over 175 items in the inventory including everything from talking clocks to large print cookbooks to modified tape recorders. The catalog is available in large print, Braille, and on cassette tape. Please send $3 for your copy to: The Store at MAB, 200 Ivy Street, Brookline, MA 02146. State your preference for large print, Braille, or cassette tape.

Products for the Blind

We have been asked to announce the following: the American Printing House for the Blind carries hundreds of products that support the independence of people who are blind or visually impaired. From Braille, large type, and recorded publications, to educational aids, tools, and supples – we have products for learning and for living. For information, and to place orders, dial 1-800-223-1839. Call between 8:00 a.m. and 4:30 p.m. Eastern time, Monday thru Friday from anywhere in the U.S. or Canada. Visa®, MasterCard®, and Discover℠ are accepted.

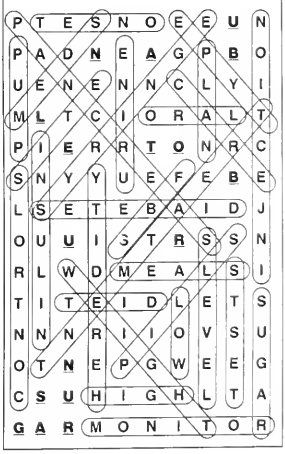
New Pamphlet

The Diabetics Division of the National Federation of the Blind now has a new pamphlet titled ***Diabetes, Complications, Options.*** This pamphlet is attractive and explains our outreach programs. The publication disseminates essential information and reaches out to anyone who has an interest in diabetes and blindness.

Free copies are available to anyone interested in helping to spread the word. The new pamphlet is great for libraries, pharmacies, physicians' offices, hospitals and so on. *Diabetes, Complications, Options* may be ordered from: the National Federation of the Blind, Materials Center, 1800 Johnson Street, Baltimore, MD 21230; telephone: (410) 659-9314.

Puzzle Solution

The hidden message is:
Unable to burn sugar



EXERCISE QUIZ ANSWERS

(Continued from page 15)

1) **False.** Even if you do not take medication for your diabetes, you can still experience hypoglycemia (low blood glucose levels) during or after exercise. That's why carrying a carbohydrate source with you is a good idea.

2) **False.** If you exercise when your blood glucose levels are greater than 250 mg/dL, your blood glucose levels are likely to increase during exercise. It is best to wait until you get your blood glucose under better control.

3) **True.** Just having diabetes puts you at higher risk for cardiovascular disease. Because of this, and other medical risks, you should always have a talk with your doctor before you start an exercise program.

4) **True.** It is best to allow time for the carbohydrate in your meal to be "stored away" as well as possible before you start to exercise.

5) **False.** You should not exercise if your blood glucose levels are below 70 mg/dL, because you are likely to experience hypoglycemia during or after exercise.

6) **False.** You need to give your body time to metabolize a pre-exercise snack, if your blood glucose levels are too low. Doing the measurement right before you start exercise won't give you enough time to do this. Try to do the measurement about 30 minutes before the session, eat a snack if needed, then wait a half-hour before exercising.

7) **False.** Although tennis provides some cardiovascular benefits, you should be doing continuous (not sporadic) exercise to gain the most aerobic benefits. Walking, biking and swimming are the best types of aerobic exercise for you.

8) **True.** If you exercise before going to bed, your blood glucose levels may drop too low while you are sleeping. If you are unaware this is happening while you sleep, you will be unable to respond to a low blood glucose attack.

9) **False.** Exercise improves your body's insulin sensitivity (ability to use insulin), which will, in turn, lower your blood glucose levels. Scientists do not know of anything that can increase your body's production and secretion of insulin.

10) **True.** The suggested goal for aerobic exercise is a continual duration of 20-60 minutes of exercise at a moderate intensity level, performed three to five times a week. You should progress slowly to achieve these goals safely.

SCORING

10 Correct: "All-Pro." You have an excellent knowledge of exercise and diabetes information.

8-9 Correct: "Pro." You have a good understanding of diabetes and exercise information. You should brush up on your knowledge.

6-7 Correct: "Amateur." You have a fair understanding of exercise and diabetes information. You should contact an exercise specialist (who is familiar with diabetes) or your physician to develop a better understanding of this area.

5 Or Fewer Correct: "Bench Warmer." You have a poor understanding of exercise and diabetes. You should attend a class on diabetes and exercise and contact your physician to develop a better understanding of this area.

(*Note:* Reprinted with permission from *Diabetes in the News*, published by the Ames Diabetes Education Center.)

SECURITY EQUALITY OPPORTUNITY NFB

Membership/Subscription/Donation Form

The ***Voice of the Diabetic*** is a quarterly magazine published by the Diabetics Division of the National Federation of the Blind (NFB) for anyone interested in diabetes, especially diabetics who are blind or losing vision. It is an outreach publication emphasizing good diabetic control, diet, and independence.

Because production costs exceed subscription rates, all donations are accepted and very much appreciated. Most people prefer membership. To subscribe without becoming a member, the institutional rate must be paid.

You may receive the ***Voice*** as a member or at the institutional rate. **Please check one:**

☐ I would like to become a *member* of the NFB Diabetics Division and, as a member, receive a free subscription to the ***Voice of the Diabetic.*** Membership fee is $5.00 per year. (Members of our Division enjoy certain advantages, such as, if side effects occur, members can be put in touch with others who have had similar experiences.)

☐ I would like to subscribe to the ***Voice of the Diabetic*** at the institutional rate ($15.00/one year; $28.00/two years; $40.00/three years.) (Higher rates reflect actual $15.00 production cost per year.)

Send the ***Voice*** in (check one): ☐ print ☐ cassette tape for the blind (at no extra cost, recorded at 15/16 IPS) ☐ both

Optionally, check this box:

☐ I would like to make (or add) a tax-deductible contribution of $__________ to the Diabetics Division of the NFB.

Please print clearly

Name ______________________________

Address ______________________________

City ______________________ State __________ Zip __________

Telephone Number (__________) ______________________________

Send this form or a facsimile along with your check to our editor:
Ed Bryant, 811 Cherry St., Suite 309, Columbia, MO 65201

Please make all checks payable to:
NATIONAL FEDERATION OF THE BLIND